The development of an online training resource for mental health professionals to involve carers in information sharing

Report for the National Institute for Health Research Service Delivery and Organisation programme

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The Report

1 Introduction

This is the second project funded by NIHR SDO\(^1\) programme from researchers at Rethink (a national mental health membership charity in England), the University of Swansea and Kings College London addressing how mental health professionals share information effectively with mental health carers. The first was a research study identifying best practices as documented in the published report *SDO/54/2003*, subsequent briefing paper ([http://www.sdo.nihr.ac.uk/files/adhoc/54-briefing-paper.pdf](http://www.sdo.nihr.ac.uk/files/adhoc/54-briefing-paper.pdf)) and publications (Rapaport et al 2006; Slade et al 2007; Pinfold et al 2007). The briefing paper has been widely referenced and included in Department of Health guidance (Department of Health, 2009) as well as a coroner’s report in Chichester covering the Larissa Edgell Inquest. In this report we refer to the first study as ‘the original NIHR SDO research’.

This current piece of work builds on the first study, addressing one of the project recommendations to develop training materials for mental health professionals. It was a specifically commissioned project by the SDO programme representing an example of extended dissemination, building on the published briefing paper to focus upon the ‘development’ element of the research and development pathway. The project has substantially changed and been extended since the original commission in 2007, as described in appendix I.

Throughout the report we use the term ‘carer’ to mean the family, friends and significant others of people with mental health problems who provide them with support and assistance. These are not care workers employed by social services, NHS Trusts or other agencies, but the group sometimes referred to as ‘informal’ carers or ‘unpaid’ carers although those terms are used increasingly less. Many do not view themselves as ‘carers’ officially but these family and friends are a significant group in terms of the roles they perform.

1.1 Aims of the project

The aim of this project was to develop training materials to support mental health professionals working in adult services in England and Wales to effectively share information with carers.

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\(^1\) The report uses a number of abbreviations in the text. A full listing is provided in appendix XII
A comprehensive consultation process focused the project plan on developing and piloting online learning materials for Mental Health NHS Trusts. During the pilot the aims were to:

1. Test usability of the site
2. Gather feedback on content of the site, identifying content gaps and collating suggestions to improve the resource
3. Assess impact of interactive course on learner knowledge
4. Document reported behaviour changes that learners planned as a result of using the resource
5. Explore how to best disseminate the resource to achieve uptake by mental health professionals across Mental Health Trusts

1.2 Project team

This project was delivered as a partnership initiative between Rethink, University of Swansea, Kings College London, the steering group and Minervation, a company selected by the steering group to build the online resource. A profile of each partner is provided below. The project manager was Áine Duggan at Rethink.

1.2.1 Rethink

Rethink is the leading national mental health membership charity working to help everyone affected by severe mental illness recover a better quality of life (see [www.rethink.org](http://www.rethink.org) for more information). Our aim is to make a practical and positive difference by providing hope and empowerment through effective services and support to all those who need us. We undertake research, provide specialist advice and information as well pilot innovative solutions to promote recovery. The Rethink research team undertake projects in partnership with academic units and have recently co-delivered the NIHR SDO programme funded carer well-being and support measure. The Rethink research team has project managed this study, leading on all aspects of consultation and data collection.

Dr Vanessa Pinfold, Deputy Director of Knowledge and Learning

Áine Duggan, Research Manager who managed this project

1.2.2 University of Swansea

The Centre for Social Work and Social Care Research, School of Human Sciences at the University of Swansea have partnered Rethink in this project. Professor Huxley was the Principal Investigator in the original NIHR SDO research. The Centre undertakes original research, most of it in the mental health field. Current projects include an NIHR SDO programme
funded study of community mental health teams, and the development of a measure of social inclusion funded by Health Technology Assessment.

Professor Peter Huxley, Professor of Social Work and Social Care

1.2.3 Kings College London

The Social Care Workforce Research Unit at King’s College London was a partner in this project. The Unit is a multi-disciplinary national centre for original research into issues relating to the social care workforce. It receives core funding from the Department of Health’s Policy Research Programme and also hosts the Department’s Social Care Workforce Initiative.

Dr Joan Rapaport, Research Fellow

1.2.4 Minervation

Minervation (www.minervation.com) were commissioned to build the information sharing with carers website. Minervation are an evidence-based healthcare company based in Oxford who have experience in e-Learning, user interface design, mental health, multimedia, service user involvement and usability testing. A small team from Minervation worked on this project.

Andre Tomlin, Managing Director and Minervation project lead
Nick Clarkson, Design
Robin Massart, IT
Douglas Badenoch, Information Science
Emily Withington, Information Science
Julia Cartwright, Consumer Involvement lead

1.2.5 Steering group

The steering group had a central role in this project. They commissioned Minervation to build the resource and were active in developing the case study material which forms the interactive lessons of the resource. The expertise of the group included mental health professionals (social worker, psychologist, psychiatrist, CPN), carers, carer support workers, service user, and members of the project team. There were 10 regular members of the steering group. Those external to the project team were:

Peter Woodhams (Carer Consultant)
Janey Antoniou (Service User Consultant)
Dr Grainne Fadden (Consultant Psychologist and Director Meridan Programme)
Dr Ryan Fuller (Consultant Psychiatrist, West London Mental Health Trust)
Jane Lawrence (Carer Support Service Manager, Rethink East Sussex)
1.2.6 Expert advisors

Alongside the steering group we drew upon the expertise of key individuals including ICT department leads in our pilot Trusts, a wider group of carers, workforce development colleagues within Rethink and representatives in other voluntary sector organisations or professional bodies. This included two carers (who wish to remain anonymous).

1.2.7 Project team responsibilities

A map of how the project developed, with the responsibilities of the two main delivery partners (Rethink and Minervation), is shown in figure one. The steering group was consulted at key stages – in particular the development of case study material, and Professor Huxley and Dr Rapaport advised throughout contributing to drafts of the resource content and commenting upon formatting issues.
1.2.8 Methodological structure and project time table

The study is a practice development project underpinned by the original NIHR SDO research undertaken by the team and additional information collected and collated during the development pathway. This project is not a scientific research project but it does use research methods and ‘action research’ principles to create the online learning resource package for mental health professionals. The stages of development (five phases in all) and rationale for the chosen methodological approaches are summarised below in figure 2.

Figure 2. Methodological development process in phases

- I: Original NIHR SDO research on mental health professionals information sharing with carers
- II: Practice survey in Mental Health NHS Trusts
- II: Key informant interviews in responding Mental Health NHS Trusts
- II: Review of current training materials for mental health professionals on working with carers
- II & V: Expert meetings with trainers and carer organisations
- V: Feedback collated from expert partners
- V: Pilot participants use site and feedback
- DECISION: e-learning package commissioned
- III: Consultation with mental health professionals
- III: Review of e-learning: packages and conceptual framework
- IV & V: Consultation with steering group, carer groups
- DECISION: Criteria for developing the e-learning resource
Phase one: Literature and policy reviewing, drawing in particular on the original NIHR SDO programme report. This provided the research team and steering group with a preliminary structure and content for the resource that would be tested in development sites with our target learners – mental health professionals during phase 3. Timescale: June 2007-April 2008. See section 2 in this report.

Phase two: Initial scoping phase to understand learning environments across the NHS and current training relating to the role of carers. A practice survey of 60 Mental Health NHS Trusts, followed up by telephone interviews of key informants. This information fed into the decision making cycle of ‘what’ format of resource to produce. The initial scoping phase also consulted mental health training providers and reviewed carer training packages to ensure this project complemented, rather than replicated, existing materials. Timescale: June 2007-April 2008. See section 3 in this report.

Phase three: Second phase development involved detailed consultation within two NHS development sites purposively selected because their CEO was supportive of addressing carer and confidentiality issues across their organisations. Consultation within the development sites with staff were used to confirm and amend the preliminary resource structure and content that emerged from phase one. Consultation routes in each site was organised to suit local practitioners using discussion groups (either mixed practitioner group or team meetings) and individual interviews. E-learning packages were also reviewed at this stage. To strengthen this phase, as it was likely the consultation attracted pro-active practitioners with a prior supportive interest in ‘carers and confidentiality’ consultation with carers was undertaken in phase 4 to understand the barriers and problems they experience. Taken together, consultation in the development sites, meetings with carer groups and the e-learning review provided a framework for the project build phase. Timescale: May - September 2008. See section 4 in this report.

Phase four: Building the resource guided by a set of criteria produced through phases 1-3 as well as a brief review of literature on learning styles to provide a conceptual framework around the new resource. There were five build phases in the development cycle (draft architecture and content; mock up of shell; fill shell with material; cross inference and integrate materials; ready for piloting). Throughout this phase there was detailed consultation with carers and mental health professionals to fine tune text (either for the information sections or the interactive films). This was important to ground the resource in the lived experiences of both carers and mental health practitioners. Timescale: October 2008 – July 2009. See section 5 in this report.
Phase five: Pilot phase to gain feedback from learners in order to improve the resource prior to widespread implementation across Mental Health NHS Trusts. The development Trusts were the first source of pilot participants but we extended recruitment to multiple sites – 13 in all. Feedback was gathered using a ‘survey monkey’ online pre- and post- survey. The pilot feedback was fed into a usability testing session with mental health professionals from one development site. Additional feedback was sought from mental health organisations and the collated responses structured the revision plan used to modify the resource to provide the final version available at www.carersandconfidentiality.org.uk Timescale: August - September 2009. See section 6 in this report.

Throughout the development pathway, more rigorous research methods could have been applied had the project been designed as a research study. However, it was commissioned as an extended piece of NIHR SDO dissemination and this report has been written to reflect that brief. Action research principles, with feedback mechanisms and iterative development phases, ensured the development cycle was grounded in the needs of the learners – mental health professionals and drew upon the areas of key concern to carers.

1.3 About this report

This report describes how we developed an online learning resource for mental health professionals. The pilot resource tool can be found at: http://rethink.minervation.net/ It will be useful to look at the resource before reading the chapters explaining how it was built. The fully revised resource can be accessed at www.carersandconfidentiality.org.uk and once again we recommend you look at the resource alongside the narrative in this report detailing how it was developed.

It is important to note that the pilot site will in time be withdrawn as its poor practice to have two near identical sites ‘live’ on the world wide web. If you are reading this report and the pilot site is unavailable please do use the revised site as your reference point.
Section 2 provides a summary of relevant policy and research literature to provide the study context. Section 3 describes the initial scoping work undertaken before firm plans for the resource were established. It includes a summary of data from the original NIHR SDO research report from the team. Section 4 details the recruitment of two development Trusts and mental health professional consultation phases. The focus of the resource was the main groups of mental health professional staff employed by Trusts (psychiatrists, in-patient and community team managers, CPNs, social workers, in-patient nurses, occupational therapists). Section 5 explains how the resource was built, combining technical specification factors with resource content. It includes the development of case studies which were filmed and edited to produce an interactive course within the resource. Section 6 examines the pilot data collected pre- and post-use of the resource from participating mental health staff and describes the usability testing phase of the resource. Finally, in Section 7 we make recommendations for dissemination and research.
2 Background

This section provides background literature and reviews key policies that affect mental health carers in England and Wales. It draws on material from the original NIHR SDO research report updated with information published after 2005.

2.1 Sharing information with carers

The sharing of relevant and necessary information between mental health professionals and carers is crucial for the operation of “safe, sound and supportive” modern mental health services (Department of Health, 1998) and a vital component of supporting carers (Department of Health, 2002). Recovery outcomes for service users may also improve where carers are given information they need to care effectively and keep well themselves (Pilling, 2002; Pharoah 2006). However, in spite of these apparent benefits, in practice in formation sharing between professionals, carers and service users can raise many problems (Arksey et al, 2002), and crucial among these is the issue of protecting confidentiality.

The Department of Health (Department of Health, 1995), professional bodies (RCP; RCN; BPS; and BASW) and voluntary sector agencies have issued guidance on the protection and sharing of information. Local mental health policies have also developed in collaboration with a wide range of allied services. It was within this context that NIHR SDO commissioned research in 2003 to identify best practice strategies for sharing information with mental health carers across England and Wales. The study occurred in the wake of data protection policies and a series of Government initiatives to support carers (Carers Act, 1995; Department of Health, 1999,a; Department of Health, 1999,b; Carers and Disabled Children’s Act, 2000; Carers (Equal Opportunities) Act 2004. More recently, the Mental Capacity Act 2005 and Mental Health Act 2007 have come into force, the 2008 CPA policy and positive practice guidance have been produced (Department of Health, 2008a) and the National Carers Strategy from 1999 (Department of Health 1999c) has been updated ten years on (Department of Health, 2008b), see Table 1 for a summary.
Table 1. History of mental health carer policy and legislation in England and Wales

<table>
<thead>
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<th>Carer Policy</th>
<th>Summary of significant points</th>
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<tr>
<td>Nearest relative – Mental Health Act 1983</td>
<td>Prioritises carer relative; discretionary powers (civil sections):</td>
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<td></td>
<td>• To request an assessment of patient for hospital admission – to which social services must respond. ASW must give written reasons if admission is not made</td>
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<td></td>
<td>• To make the application to detain the patient (if doctors agree)</td>
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<td></td>
<td>• To object to a treatment or guardianship order</td>
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<td></td>
<td>• To seek to discharge the patient</td>
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<td></td>
<td>Rights to information about detention. Rights to attend tribunal.</td>
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<tr>
<td>NHS &amp; Community Care Act 1990</td>
<td>Introduces the term carer</td>
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<td>Promotes carer involvement in patient care</td>
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<tr>
<td>CPA &amp; carer policy – Department of Health 1990/95/99c</td>
<td>Promotes carer involvement in Care Programme Approach (Department of Health 1990; 1999c)</td>
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<td></td>
<td>Introduction of framework to support development of confidentiality policies available to carers and service users (Department of Health, 1995)</td>
</tr>
<tr>
<td>Carers (Services &amp; Recognition) Act 1995</td>
<td>Defines carer: person who provides substantial care on a regular basis (excludes employment and voluntary body arrangements). Introduces carer’s right to ask the local authority (social services) for an assessment of own needs. Guidance urges local authorities to inform carers about the carer’s assessment (SSI, 1996)</td>
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<tr>
<td>NSF Standard 6 Department of Health 1999a</td>
<td>National Service Framework (NSF). Provides the carer of someone on CPA with:</td>
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<td></td>
<td>• An annual (at least) assessment of caring physical and mental health needs</td>
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<td></td>
<td>• His/her written care plan</td>
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<td>Caring about Carers Department of Health 1999b</td>
<td>Injection of funding to local authorities to provide carer respite services.</td>
</tr>
<tr>
<td>Carers &amp; Disabled Children’s Act 2000</td>
<td>Empowers local authorities to provide:</td>
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<tr>
<td></td>
<td>• Carer services</td>
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<td>• Short-term break voucher schemes</td>
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<td>• Direct payments to carers</td>
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<td>• Local authorities can charge carers for services received.</td>
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<tr>
<td>Mental Health Act 2007</td>
<td>Nearest Relative (NR) from 1983 Act retained, identified from a legal hierarchy of relatives, is often the patient’s carer. When under section, unless the patient objects, hospital managers have a legal duty to provide the NR with information regarding the legalities of the section. Also introduces new provisions regarding displacement of unsuitable NRs.</td>
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| Carers (Equal Opportunities) Act 2005 | Local authority (social services) duties:  
- To ensure carers know about their rights  
- To promote strategies to help carers across local authority services |
| Mental Capacity Act 2005 | Enables people to appoint a Lasting Power of Attorney (LPA) in advance of incapacity to make health and welfare decisions – thus in some cases carers may be appointed. |
| National Carers Strategy 2008 | Outlines government commitment to carers particularly in relation to provision of respite breaks, access to information through telephone helplines, and training through a new caring in confidence programme. A standing commission on carers has also been convened to oversee the implementation of this strategy. |

2.2 Information sharing: Ethical considerations

Non-malificence and Beneficence are important principles in medical bioethics (Beauchamp and Childress, 1994). Non-malificence requires that no harm be intentionally inflicted. Beneficence requires proactivity to prevent harm. Harm prevention and the promotion of good or best interests in respect of patient care are traditionally core elements of ethical practice.

Health professionals are required to protect the right of an individual’s privacy in relation to his or her psychiatric condition, and are trained in ‘patient confidentiality’ rather than information sharing (Leggatt, 2001). They are concerned to keep the trust of the patient (BMA, 1999) and fear being sued (Leggatt, 2001), although litigation is rare (Department of Health, 2001). Yet rights to confidentiality are not absolute, may be breached in cases of societal and public interest (W v Edgell [1990] 1 All ER; 835), and need to reflect social responsibilities (Etzioni, 1999). Furlong and Leggatt (1996) suggest a conceptual framework is needed to balance the rights and interests of patients with the needs and responsibilities of carers. Confidentiality is seen as a particularly taxing ethical issue when the family’s involvement appears justified but the service user is withholding consent (Szmukler and Bloch, 1997).

Carers need some kinds of information to enable them to provide effective care (Fruin 1998; Dowling 1995; Foundation of People with Learning Difficulties, 2002), to access their entitlements to an assessment of their own needs, services and welfare rights and to make decisions about how
they want to lead their lives. They also need to be listened to, not only to contribute to the professional assessment of the service user's care but also to elicit from professionals information pertinent to informal care. However, carers and relatives may also be reluctant to share information with professionals in certain situations. These include not only feelings of family loyalty but in addition, fears of hospital admission, indiscriminate sharing of their confidences especially with the person cared for and reprisals within close relationships (Rapaport, 2002). Carer reluctance to share information for whatever reason is likely to restrict meaningful dialogue between professionals and carers.

Mental health service users face particular restrictions on their private lives. The right to privacy is essential in the interests of maintaining self-respect and enabling human interaction without constant social breakdown (Nagel, 1998 cited in Backler, 2001). 'Patient confidentiality' is an essential component of the therapeutic alliance between the service user and professional to engender service user trust and facilitate recovery (Backler, 2001). 'Patient' autonomy, the right of a competent person to make decisions about his or her own life, is becoming an increasingly important part of healthcare policy. Significantly, an adult patient's right to refuse medical interventions is well recognised in common law (BMA, 1995).

'Patient' privacy and autonomy are vital components of mental health recovery. However, 'patient' privacy and autonomy principles are subject to restrictions because of:

- doubts about an individual's capacity to make rational judgements;
- public and personal safety considerations;
- the treatment criteria of the Mental Health Act 1983 (where a person is detained).

The carer's need for information to support the caring role further threatens service user autonomy and privacy. Firstly the service user may have no choice about the identity of the carer, or the right to refuse to have one. The position is further complicated by disaffected and abusive relationships (MHAC, 1991). Professionals have concerns about disadvantaging the service user by sharing their personal information with the carer.

### 2.3 Information sharing: Overview of principles and governing frameworks

Confidentiality is the cornerstone of the 'therapeutic alliance' which professionals aim to forge with service users to aid recovery. Clinicians must therefore be aware that any breach of confidentiality may jeopardise the service user's trust and thus the therapeutic relationship. However, rights of confidentiality are not absolute and may be overruled in certain circumstances such as risk to the service user and public protection. In mental health contexts, a decision to share information with a carer against the patient's wishes may be particularly complex. In such circumstances, Szmukler and Bloch (1997) suggest an ethical framework to guide
information sharing with carers which also takes account of the therapeutic relationship. This includes:

- An assessment of the service user’s mental capacity to make a decision regarding the disclosure,
- An assessment of the nature and quality of the carer and service user relationship in the longer term,
- An assessment of the care context, and
- Recognition of the carer role and carer entitlements.

The sharing of personal information is also governed and influenced by a substantial list of policies, laws and legal and professional codes, some key aspects of which are considered here. The principle of obtaining a person’s consent wherever possible when disclosure is contemplated is paramount. Under the Data Protection Act 1998, people using services have a right to know that their health and personal records will:

- Be regarded as confidential and kept in accordance with the law,
- Be used only for the purpose intended and not for other purposes without their authorisation, unless, wherever possible they have given their explicit and valid consent to such disclosure.

Where consent is not forthcoming, disclosures are sanctioned in the interests of public safety and/or that of the individual, and disclosures required by law or made in legal proceedings. Given the public safety position, it is sobering to note that an analysis of twenty-eight inquiry reports from 1988 - 1997 revealed that carers and people close to the service user were often the victims of psychiatric homicides (Reith, 1998).

However, the frameworks supporting carer access to information for legal and care purposes are complex. Carer rights and entitlements are embedded in carer, mental health and mental capacity legislation, policies and codes.

### 2.3.1 Carers Act 1995 and National Service Frameworks for Mental Health

A carer is legally defined as an individual who provides or intends to provide a substantial amount of care on a regular basis. He or she is entitled to ask the local authority to carry out an assessment of need to enable him or her to provide care for the person in question. The National Service Frameworks (standard 6) introduced the right of carers of people with severe mental illness to an annual assessment of ‘their caring, physical and mental health needs’, and their own written care plan (Department of Health, 1999a; 69). The guidance further states that the carer’s plan should include:
‘information about the mental health needs of the person for whom they are caring, including information about medication and any side effects which can be predicted, and the services available to support them’ (Department of Health, 1999; 72).

Standard 6 did not consider the issue of patient consent. Whilst it did recommend local arrangements be made to ensure that a user’s and carer’s plans are considered together, it is difficult to conceive how a carer would be able to understand what all his or her care and personal welfare needs are without some relevant clinical information. Thus, in line with the policy statement in standard 6, a carer arguably requires certain information for the purpose of supporting a robust carer assessment to enable him or her to provide safe effective care.

2.3.2 Mental Health Act 2007 and code of practice (England and Wales)

The nearest relative (NR), identified from a legal hierarchy of relatives, is often also the patient’s carer. The NR has discretionary powers governing the patient’s hospital detention (civil sections only) and as such is recognised as an important patient safeguard. Unless the patient objects, the hospital managers have duties to provide the NR with information regarding the legalities of the section, including community treatment orders (CTO) although the NR can not object to the use of a CTO.

2.3.3 Mental Capacity Act 2005 and code of practice

The MCA provides a legal framework to empower and protect people who may lack capacity to make particular decisions for themselves, whether on a temporary or permanent basis and however caused. It identifies who can make decisions in which situations and provides guidance on the processes involved. New provisions allow people (adults) to plan ahead for a time when they may lack capacity. The MCA is governed by five overarching principles, three of which are considered below and introduces new proxy decision making roles which have specified rights of access to service user information.

In respect of decisions to share information with carers, the principles of assumption of capacity and support to help the service user reach a decision on the issue of consent, are paramount. Psychiatrists will be well versed in the two-stage test of capacity set out in the Code of Practice:

- ‘Does the person have an impairment of mind or brain, or is there some sort of disturbance affecting the way their mind or brain works?'
- ‘If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?’
• In reaching a decision, psychiatrists and allied professionals will need to ask:
  
  • Does the person have a general understanding of what the decision concerns?
  
  • Does he or she understand the consequences of making or not making the decision?
  
  • Can he or she weigh up the relative importance of the information?
  
  • Can he or she communicate his or her decision, if necessary, with assistance?

The new proxy decision making roles of Lasting Powers of Attorney (LPA) and Court Appointed Deputy have rights of access to relevant service user information to enable them to fulfil their respective functions. Court Deputies may also be appointed for children. An LPA is appointed by the service user to make decisions on his or her behalf in the event of incapacity. An appointee may be authorised to make decisions on personal welfare, healthcare or financial decisions. If a carer is also an LPA for one or more of the LPA functions or a court appointed deputy, he or she will be entitled to receive relevant confidential information for the purposes of performing his or her duties.

Professionals and proxy decision makers have duties to abide by the Code of Practice and act in a person’s ‘best interests’. The MCA potentially provides service users, carers and professionals with opportunities to strengthen alliances by creating opportunities for advance decision making and giving the service user greater control (Manthorpe et al, 2008). If the carer is identified in a written statement of preferences or as an LPA, a framework of ethical information sharing within the therapeutic relationship is arguably also more clearly defined.

2.3.4 Children and Young People

Parental involvement in a child or young person’s care and treatment is regarded as good practice in respect of 16-17 year olds, and customary for children under 16. However, children under 16 years of age are not automatically presumed to be competent but the courts have stated that they will be considered competent to give valid consent to a particular intervention if they are found to have ‘sufficient understanding and intelligence to understand fully what is proposed’ (‘Gillick competence’). Thus there is no specific age when a child becomes competent to consent to a treatment or intervention by him or herself and without parental involvement. It depends on the level of the child’s understanding and the seriousness and complexity of the proposed treatment options (Department of Health, 2001). However, in reaching decisions to involve or not involve
parents or those with parental responsibility, clinicians will also need to weigh up the care context and best interest factors.

2.4 Research literature

Research and literature published since the original NIHR SDO research project echo findings from the report (SDO, 2006): policy and legislation remains ambiguous and professionals are still provided with little clarity on how to deal with information sharing dilemmas in practice within legal and ethical obligations. The literature continues to push for more integrated working between professionals and carers and acknowledges a change in culture is required to achieve this (Slade et al, 2007; Stanbridge and Burbach, 2007).

Though professionals may have an understanding about the value of involving carers, they continue to find it difficult to balance service user confidentiality and carer needs (Scourfield, 2005; Gray et al 2008). For example, Gray et al (2008) found that professionals were uncertain about offering carers’ assessments due to concerns about breaching service user confidentiality (particularly in circumstances where service users withheld consent to share information with carers or family members). This indicates a continued lack of confidence amongst professionals in their ability to manage information sharing dilemmas, creating barriers between professionals and carers. O’Hara comments that social workers are concerned that they might be in breach of the Data Protection Act (DPA) 1998 without thorough understanding of information sharing in relation to child protection issues specifically but also support to families more generally (O’Hara, 2009).

Family interventions have been put forward as a way to reduce these barriers and more inclusive three way working between carers, service users and professionals (Gamble, 2007; Stanbridge and Burbach, 2007 & 2009). Such interventions are targeted at the entire family, not just carers. Closer working with families has clear benefits: providing opportunities for professionals and families/carers with opportunities to engage, access to appropriate service provision and education about the illness and different coping strategies (Gamble, 2007) as well as providing opportunities for professionals to learn more about the service user and family dynamics. This integrative approach moves away from separate carer support services that sit outside the immediate care team as recommended by Rapaport et al (2006) and provides professionals greater opportunities for contact with carers. Family interventions could help break down barriers between carers and professionals but its associated literature does little to address the specific issue of information sharing dilemmas and confidentiality.

A knowledge-gap is still present amongst professionals in how to work together with families and carers. On the basis of our original NIHR SDO research Slade et al (2007) published a framework for best clinical practice outlining how to share information with carers where consent is withheld. The incorporation of the framework into local operational policies would help create a shared understanding of consent, the types of information that can
be shared without consent and increase professional accountability. Stanbridge and Burbach (2007) argue that mental health services require a comprehensive workforce development strategy in order to equip staff to work closer with families and carer - including a formal strategy endorsed by management and a ‘champion’ to take it forward, training for clinical teams and access to supervision to support implementing the training. A review of the a face to face family intervention training they delivered to mental health staff showed that the staff found the interactive elements of the training useful (i.e. role plays); staff had increased the number of appointments they had had that included a carer/family member following the training, this contact had in turn boosted their confidence in working with these groups.

The Royal College of Psychiatrists (Hervey & Ramsay, 2004) have issued guidance on how to assist better communication between carers and professionals (e.g. carer’s steering groups to help promote carer involvement). This represents a move away from carers representing views of the individual they care for and towards a wider promotion of carer issues and awareness raising amongst professionals. Gray and Robinson (2009) also provide some good practice guidelines on how to increase together working between professionals and young carers, suggesting more informal points of contact such as young carers groups and befriending as approaches to break down barriers and increase support for young carers.

The Department of Health (2009) recently published guidelines on supporting information sharing with carers. It clarifies the role of Caldicott Guardians in the NHS and local authorities, a senior person within each organisation who is able to provide advice to all grades of staff that are faced with making these decisions. They ensure that local policies are in place and that organisations adhere to the legal framework and the Data Protection Act 1998. The document, again provides little practical guidance on dealing with these issues but does show that information sharing remains on the NHS agenda.

There have been moves for greater joint working between professionals and carers, and raising awareness of carer issues more widely, however practical information on how to address information sharing dilemmas and what to do when a service user withholds consent is still sparse.

### 2.5 Discussion

This section has summarised some of the key documents that the learning resource will need to reference. The project team will need to plan how to use this information carefully to ensure a sufficient level of detail is provided without overloading the learner. Layering of information maybe required whereby short summarises are provided, linking to longer texts as reference.
2.5.1 Summary

Information sharing with carers is dealt with in professional codes of practice, NHS Trust policies and government guidance documents. The principles of patient confidentiality are set out in law. Research shows, however, that in practice sharing information with carers can be challenging for mental health professionals, service users and carers.

2.5.2 Limitations

The policy and literature review covers only England and Wales. Therefore, the information contained within the learning resource will only be suitable for practitioners in England and Wales.

2.5.3 Next steps

The policy frameworks supporting carer access to information are referenced within the information sections of the training resource. Relevant policy documents are both summarised and linked to for those learners wanting access to the full text. Research articles are also cited for those learners who would like to follow up the basic information provided with more detailed reading. The screen shot below shows one such page in the resource.
3 Initial scoping phase

This section outlines the first phase of development of the learning resource. Initial scoping with NHS Trusts was carried out to understand how their learning environments were structured and what current training on carers was offered so that the new resource would complement existing structures. The scoping was carried out from June 2007 to April 2008.

3.1 Objectives

The main objectives of this phase were:

- To assess the current training practices of NHS Trusts with regard to carers, both in general and specifically on the issue of carers, confidentiality and information sharing in mental health;
- To assess the learning needs and preferences of mental health professionals from a variety of professional backgrounds as reported by key informants in the NHS;
- To identify sustainability issues related to long term uptake of a learning resource within the NHS;
- To identify possible pilot sites;
- To explore the original research data set for information to assist in the development of the new resources.

3.2 Method

This phase was conducted in three parts. The focus was information gathering to inform practice development and thus the data collection tools reflect this approach.

3.2.1 Practice survey

The practice survey questionnaire was developed by the team and sent to the 72 mental health Trusts through the Chief Executive Officer (CEO) office. The cover letter requested that the survey was passed to the appropriate training or carer development lead in the Trust. Respondents were asked to return the brief survey to the Rethink research team in a freepost envelope. Non-responding Trusts were chased for responses via the CEO office by telephone.

The practice survey asked 4 questions.

- What training was delivered to staff on working with carers?
- What type of training was delivered to staff on working with carers?
- What are preferred learning formats in the Trust across different professional groups?
- Interest in the project – and expressed interest in being a pilot site.

We received responses from 26 Trusts (36%).

3.2.2 Telephone interviews

We interviewed 17 NHS managers from 16 different Trusts. These were the key informants who responded to the survey, and provided follow-up contact details. They were semi-structured telephone interviews, lasting approximately 30 minutes, recorded through notes taken by the interviewer. The interview notes were analysed by two members of the project team to produce a summary analysis of key themes.

3.2.3 Initial consultation and review

The third element of this phase was to consult with experts who produced training materials for mental health professionals, particularly professional bodies, and review current e-learning packages to establish a number of guiding principles for the project. We also re-visited the original research data to draw on the perspectives of service users, carers and mental health professionals when drafting ‘mock-up’ resources to test with development sites.

3.3 Practice survey data

The responding key informants carried different responsibilities within their Trust, as shown in Table two. Seventeen suggested they would be interested in being pilot sites in this project, the remaining nine that they might be interested.

<table>
<thead>
<tr>
<th>Job roles of respondents</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directors or senior managers of mental health services / social care services</td>
<td>10</td>
</tr>
<tr>
<td>Managers with responsibility for Patient and Public Involvement</td>
<td>5</td>
</tr>
<tr>
<td>Workforce Development leads</td>
<td>4</td>
</tr>
<tr>
<td>Family intervention or carer development posts</td>
<td>3</td>
</tr>
<tr>
<td>CEO 1</td>
<td>1</td>
</tr>
<tr>
<td>Team leader</td>
<td>1</td>
</tr>
<tr>
<td>Not known</td>
<td>2</td>
</tr>
</tbody>
</table>
3.3.1 Current training on carer issues

Considering current provision, 6 responding Trusts (23%) had no training on working with carers specifically, and 8 (31%) had no specific training covering information sharing with carers including confidentiality issues. Respondents in Trusts without access to specific training on this subject commented:

“This is an area of practice that causes a lot of dilemmas for professionals and support staff within their roles. It is also highlighted in serious untoward incidents/complaints where information was not shared and should have been ...” (ID1; Business manager LD and MH services)

“Neglected area of training and development and needs to be addressed” (ID11: CEO)

“We have an info sharing policy which staff are made aware of. We only offer out-patient treatment...therefore info sharing with carers is not so much an issue” (ID16: PPI lead)

Even though many Trusts had no specific training on information sharing with carers, the topic was covered, in all but one Trust, through on-going learning and development routes such as supervision, team discussions and workshops or talks (see figure 3). In two Trusts, it was covered by the Trust training team as part of confidentiality training, where the focus is patient confidentiality and record keeping.

Figure 3. Current training on carer related issues

Where specific training on carer related issues is provided, 75% of Trusts involve carer trainers so that staff can learn from their direct experiences. Several respondents explained the importance of carer and service user involvement in staff development:

“One of our compulsory training requirements is a 3 hour ‘In my shoes’ session which is run jointly by service users and carers. In addition, service users and carers are involved in delivering part of our induction programme.
for new staff. We have involvement (financial, managerial and operational) with other agencies including a Local Authority and local Acute Trust in a project called Learning to Involve which is specifically aimed at increasing service user and carer involvement all aspects of Trust work including staff development” (ID8: Assistant Director, workforce planning and development)

Other Trusts provide information sharing training through central Trust training teams at induction (2 sites), within CPA training (5 sites) and where staff are involved in family work training (2 sites). The majority of this training uses a face to face format. The mean number of reported training delivery mechanisms for information sharing modules was 2.5 (median 2).

3.3.2 Preferred learning styles

Learning and development activities are constantly evolving across the NHS linked to the NHS Knowledge Skills Framework. The survey asked respondents to indicate current preferences for how formal learning opportunities were delivered, not only on carer issues, but any subject. Responses were provided by 24 Trusts. For each staffing group we had missing data as shown in figure 4, alongside the other responses. A range of preferences are shown with mentoring and supervision reportedly favoured by psychiatrists and support staff, whilst managers were viewed to prefer taught courses and key workers liked e-learning.

Figure 4. Learning formats by professional group

The survey also asked respondents to indicate Trust wide support for learning. Eight respondents did not complete this question. Of the remaining Trusts 14 indicated that ad hoc training was supported, 14 that e-learning was supported, 13 supported mentoring and supervision, 12 taught courses, 12 action learning sets, one a blended learning approach and one work-based learning. Specific comments included:

<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrists</td>
<td>14</td>
</tr>
<tr>
<td>Community based team managers</td>
<td>14</td>
</tr>
<tr>
<td>Ward managers</td>
<td>13</td>
</tr>
<tr>
<td>Key workers (SW, CPNs, in-patient nurses)</td>
<td>12</td>
</tr>
<tr>
<td>Support staff</td>
<td>1</td>
</tr>
</tbody>
</table>

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"When motivation to learn more about the subject is high, all types of training are acceptable. If it is low, training for any group needs to be formal and mandatory". (ID 5: Clinical lead for carers).

“We offer a range of learning methods to suit individual learning styles. The majority of staff do not have time to attend short courses” (ID19: Education and Training manager)

“It is difficult to separate this out in relation to each professional group, and it varies depending on the topic. I presume you are interested in this in relation to confidentiality only. In our experience, information-sharing/confidentiality training cannot be done through e-learning. It requires face to face discussion of complex scenarios” (ID7: Director of family programmes).

3.4 Telephone interviews

The NHS managers interviewed (n=17) were from a variety of different posts within the Trust. The request for an interview was followed up by a CEO in one Trust, workforce development managers in 3 Trusts, Heads of Patient Experience in 2 Trusts and staff involved with family intervention programmes in another 2 Trusts.

Firstly, the interviews explored whether the topic area needed further addressing in their Trust. All but two participants agreed that there was a need for specific training in carers and confidentiality, given its intrinsic place in working with service users and carers. Of the other two participants one did not answer this specifically but did emphasise “A clear and consistent policy is where it all starts – training is just one element” (ID16: Workforce Development), and the second participant felt she could not answer the question as the issue had not been raised through a training needs analysis. It was mostly viewed as an issue that required further attention:

“An easy answer – yes there is definitely a need. We have lots of issues via complaints – carers and relatives bemoaning that they were not given specific information” (ID13: Business manager LD/MH)

“There is definitely a need, the issue crops up all the time”’ (ID9: CPA manager and practice educator)

A clear theme on the problem of reconciling views of service user and families was raised, alongside professional confidence on when and what to disclose. Training was provided as one solution. The need for new resources to complement existing activities such as induction talks from carers and booklets on confidentiality that all staff have access to locally was also emphasised. Rethink’s proposal for a new resource was welcomed by all participants. However, cautions included:

- New resources should complement existing work;
• Support required was in how to deal with complex situations as well as confidence that decisions will be backed up by managers when on occasion things go wrong;
• Challenging practice requires a lot more than training – Trust has a low compliance on their policy of involving carers;
• Training alone will not solve the problem.

Secondly, the interview addressed current approaches to learning and development locally. Participants reported that their Trusts were using a wide range of training methods. For example:

“The Trust uses a wide range of methods – as it recognises different people prefer to learn in different ways, ranging from formal courses, through to specific workshops, to some self-directed learning. Throughout, carers are involved in all training related to carers’ issues”. (ID2: Carer development manager)

When asked about the barriers to providing training participants provided a long list of 15 factors. These are summarised in Table 3.

Table 3. Participant views on barriers to training

<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of Trusts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of time</td>
<td>9</td>
</tr>
<tr>
<td>Money – expensive to take staff away from work</td>
<td>6</td>
</tr>
<tr>
<td>In-patient staff particularly challenging: shift working, bank staff; vacancies unfilled; night workers.</td>
<td>6</td>
</tr>
<tr>
<td>Large geographical area to cover – travelling to training a barrier</td>
<td>5</td>
</tr>
<tr>
<td>Difficulties sustaining learning</td>
<td>3</td>
</tr>
<tr>
<td>Lack of incentive to change practice / poor motivation to learn</td>
<td>4</td>
</tr>
<tr>
<td>Competing with mandatory training – less capacity for optional modules</td>
<td>2</td>
</tr>
<tr>
<td>Information overload, guidance always changing, no time to absorb new learning</td>
<td>2</td>
</tr>
<tr>
<td>Large staff team so hard to ensure they all get training they need</td>
<td>2</td>
</tr>
<tr>
<td>Training is inaccessible – too difficult to access and inflexible</td>
<td>2</td>
</tr>
<tr>
<td>Difficulties implementing learning</td>
<td>1</td>
</tr>
<tr>
<td>High staff turn over</td>
<td>1</td>
</tr>
<tr>
<td>Difficult to get teams together for team learning</td>
<td>1</td>
</tr>
<tr>
<td>For e-learning challenge i.e. poor IT skills among staff</td>
<td>1</td>
</tr>
<tr>
<td>Difficulties in monitoring and evaluating learning outcomes</td>
<td>1</td>
</tr>
</tbody>
</table>

The responses focused predominantly on issue such as time and cost implications. Lack of time in particular was a concern that was echoed by a number of participants who expressed the view that it was extremely difficult to release a number of staff together for training, particularly for in-patient settings.
"The main problems are people not having enough time to go on training; training not being accessible (ie not on site), nor suitably flexible. It is also difficult to ensure that everyone (850 staff) gets access to all the training they need, and that training is sustained."  (ID13: Business manager LD / MH)

There was also concern about competition for staff time and the need to prove that training would be useful to staff practice.

"The key problem is being able to release people from the wards. Any new training has to compete with the demands from mandatory training. We would have to prove that (new learning) would have a direct impact on in-patient care". (ID11: Acute unit manager)

"Any learning materials will need to be portable and flexible, that move away from the classroom and large collections of people, and cuts down on travel’ (ID5: Workforce Development)

The interviews also tested respondent views of preferred learning mediums. A summary is provided in Table 4. Each method has advantages and drawbacks.

Table 4.  Reported learning style preferences within each Trust to deliver information on working with carers (n=16)

<table>
<thead>
<tr>
<th>Learning style</th>
<th>Preferred option</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD-Rom</td>
<td>3</td>
</tr>
<tr>
<td>Online internet based</td>
<td></td>
</tr>
<tr>
<td>Either CD or online</td>
<td>2</td>
</tr>
<tr>
<td>Workbook</td>
<td>1</td>
</tr>
<tr>
<td>Face to face training delivered with carers</td>
<td>5</td>
</tr>
<tr>
<td>Peer-learning</td>
<td>0</td>
</tr>
<tr>
<td>Preference not specified – all supported</td>
<td>2</td>
</tr>
</tbody>
</table>

Self-paced learning was supported by 8 Trusts as a preferred training format as it addresses concerns linked to time and resource constraints. The key problems of online internet based learning packages are computer literacy of staff, access to computers at work that are of sufficient quality to enable learners to quickly navigate a learning package and concerns that this medium will not have the impact of carer trainers.

"CD ROM and e-learning particularly good for younger staff adept with IT and those working on in-patient wards”. (ID7: Clinical lead for carers)

"This would be useful if it is interactive; contains real live scenarios as well as the law (data protection etc); the CD-ROM itself can be used for team as well as individual learning – to increase its flexibility and encourage team support” (ID1: Training manager)

"The key advantages have been noted. The Trust has the equipment and recently developed the culture of e-learning and staff participation can be
tracked, qualifications gained. The key drawback is that there are no immediate opportunities for carer involvement. This too could work as most staff are computer literate and have access to IT. It would share the advantages of being flexible, cheap and accessible” (ID10: Training coordinator)

However, limitations of the CD ROM were noted because it is a static unchangeable resource. A web-based resource offers more flexibility, although access to quality computers in work hours is a significant barrier.

"This is the preferred approach to learning as the material can be amended and updated as necessary, and not ‘frozen in time’ like any CD ROM or workbook. The key drawback is that updating web based learning materials does have resource implications” (ID7: Clinical lead for carers).

"Again a useful option as part of a package of learning approaches. The Trust is already using e-learning packages. The main advantage is that they are accessible and flexible – and can be used by staff on night shifts, who would find it difficult to attend direct learning programmes”. (ID14: Education and Training Manager)

The most popular training method for modules about carers was face to face training involving carers because it has impact, can deal with complex subjects through interaction and discussion and is shown to make a lasting impression on learners when delivered well.

“This is a preferred option. The Trust has positive experience of involving service users and carers in clinical learning. The ideal package would be a reflective session with carers followed by a unit of work where staff can work through practical cases” (ID10: Training coordinator)

Overall there was a clear understanding that the way staff learn is changing, and flexibility is key to cater for the different learning preferences of staff and the resource constraints placed upon teams both in term of time – releasing staff – and the financial cost. The interviewees were positive about the proposed Rethink resource and felt it could be integrated into existing training and used to increase the number of learning options available to staff.

"Flexibility and accessibility are the key criteria – adopting as many different approaches to match different learning styles as possible”. (ID12: Manager of mental health services)

“The initiative would fit in with how the Trust wants to develop is learning – with more emphasis on people taking responsibility for their own development. Another advantage of any distance learning is that it could support workshop activities, if people had reviewed material beforehand, they would be better prepared at the workshop and gain more from it”. (ID7: Clinical lead for carers)

Finally the interviews wanted to capture recommendations for embedding the resource in current practice and sustaining learning. Linking the training to professional development portfolios was viewed as central to these tasks.
3.5 Initial consultation and review

Extended consultation and review took place in three phases. The first part focused on meeting relevant experts externally and internally within Rethink; the second part involved the review of current learning resources on the issue of confidentiality and information sharing with carers and finally the original NIHR SDO research data set and report were re-visited.

3.5.1 Expert meetings

External meetings were arranged with four experienced educators in mental health from the Royal College of Psychiatrists, BASW, City University and BMJ learning. These meetings assisted the project in gathering information on how other professional development programmes were approaching the development of learning materials. All were developing e-learning packages. It became clear from these early meetings that there was a firm move towards producing self-paced e-learning materials that allowed users to learn at their own pace and at a time that was convenient.

Within Rethink there is extensive experience of working with carers. A range of departments were approached for advice and feedback on ideas about producing the learning resource. Staff within the Workforce Development Team provided information on current practice and trends within training and learning resource development. These meetings again emphasised the wider trend towards producing e-learning materials. The main reason cited for this echoed the reason specified by those who took part in the external meetings and included the drive for producing sustainable cost effective training packages which could be modified to take account of changes in practice and policy. E-learning was mentioned as an effective ‘future proof’ mechanism for producing training materials in comparison to other means such as paper based resources. Meetings were also held with staff within the Rethink Membership and Participation department and the carers’ forum, which again helped to place the need for the resource in the context of service users and carers’ experiences. Four carers involved in the governance of Rethink were also consulted.

These experts helped to identify key resources for the project to source and review. They provided guidance on the most effective way to present information and learning materials to appeal to mental health professionals to build confidence around dealing with information sharing.

3.5.2 Review of materials addressing carers and confidentiality issues

Relevant materials were reviewed to supplement the information gathered in the original NIHR SDO funded research project. A summary of these resources is provided in Table 5.
### Table 5. Materials addressing carers and confidentiality

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
<th>Content</th>
<th>Access</th>
<th>Useful features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partners in Care training materials</td>
<td>Package written by Mike McClure. It contains six modules and is in the forms of a folder</td>
<td>Modules on: carers; partnerships; young carers and families; caring for specific conditions; communication; carers in training</td>
<td>Available to purchase through the Partners in Care website</td>
<td>The materials are written in an accessible manner. The external resources are very useful for signposting.</td>
</tr>
<tr>
<td>Partners in Care leaflets – series of four</td>
<td>Paper resources produced by the Princess Royal Trust for Carers and Royal College of Psychiatrists</td>
<td>Three checklists for carers, mental health professionals and service users on best practice in working together. Leaflet on carers confidentiality and information sharing</td>
<td>Free to download through website</td>
<td>The checklists provide useful guidelines written in a succinct manner.</td>
</tr>
<tr>
<td>Meriden Family Programme Caring for Carers</td>
<td>The aim of this programme is to train staff teams and carers to deliver family education and support programmes within their local communities</td>
<td>The programme covers a number of modules including: Experiences of caring Communication in families Communication with professionals Problem solving</td>
<td>The programme is run by Birmingham and Solihull Mental Health Foundation Trust</td>
<td>The Information sharing section uses some particularly useful vignettes, which are interactive, and useful in terms of reflecting on practice.</td>
</tr>
<tr>
<td>Trust policies</td>
<td>These documents detail individual Trust policies on confidentiality and mention carers</td>
<td>They contain details of what is expected of health professionals with regard to confidentiality in these Trusts</td>
<td>Available within the specific Trusts</td>
<td>They are outlined in an accessible manner with links to further useful sources of information.</td>
</tr>
<tr>
<td>Resource Type</td>
<td>Description</td>
<td>Availability</td>
<td>Notes</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>----------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>General Medical Council guidance on confidentiality</td>
<td>This outlines guidance on preserving confidentiality</td>
<td>Freely available online through the GMC website</td>
<td>These guidelines are written for medical doctors, the language is succinct and contains a frequently asked questions section</td>
<td></td>
</tr>
<tr>
<td>British Medical Association Toolkit</td>
<td>This toolkit identifies the key factors which need to be taken into account when decisions are made in relation to confidentiality</td>
<td>Freely available on the BMA website</td>
<td>This resource is written in a very accessible manner and offers key points to consider about specific situations</td>
<td></td>
</tr>
<tr>
<td>NHS code of practice on confidentiality</td>
<td>This outlines the requirements for preserving confidentiality for NHS professionals</td>
<td>Freely available in hard copies and online</td>
<td>These guidelines are clear and written in a professional manner to appeal to health professionals</td>
<td></td>
</tr>
<tr>
<td>BPS code of Ethics and Conduct</td>
<td>The operating guidelines for psychologists in Britain</td>
<td>Freely available through the BPS website</td>
<td>The guidelines are written in an accessible yet professional manner</td>
<td></td>
</tr>
</tbody>
</table>

A number of resources did provide practical ‘tips’ on how to deal with information sharing dilemmas but most dealt only with principles. We
reviewed the codes of conduct of professional bodies such as the General Medical Council and the British Psychological Society. Obviously the purpose of such codes is to offer overarching guidance rather than practical means of dealing with day to day situations that arise in practice. Confidentiality policies of a number of individual Trusts (e.g. Sussex Partnership Trust, Cambridgeshire and Peterborough Foundation Trust, Central and North West London Mental Health Trust) were also accessed. These policies again provided excellent guidance but understandably were lacking in providing practical strategies for dealing with information sharing dilemmas.

We concluded that while there was a lot of information available from a range of sources on the issue of confidentiality and information sharing with carers, these sources are dispersed across many documents. There were no interactive materials illustrating information sharing dilemmas and practical strategies to address them.

### 3.5.3 Original research data

In the scoping phase, the project team identified material found in the original study that could be used in this project. We focused particularly on the perspectives of service users, carers and mental health professionals and the solutions they provided to overcome information sharing barriers. See appendix II for extracts of data from the original NIHR SDO research report. (The full data set and analysis can be found at: [http://www.sdo.nihr.ac.uk/files/project/54-final-report.pdf](http://www.sdo.nihr.ac.uk/files/project/54-final-report.pdf)). These data are important as they contribute to both the information architecture of the resource (see section 5) and provide themes which were followed up in discussion groups with staff in the development phase (see section 4).

The service user data suggest there are no single models that can be applied to information sharing in mental health; individual solutions that are acceptable to all involved stakeholders are required. A number of recommendations from service users on how to share information and how to support carers emerge:

- Consent from service users should be collected before information is shared with carers, including the use of advance agreements;
- Consent should be regularly reviewed;
- Service user reservations regarding carers receiving information about their care and treatment should be taken into account when decisions are made by professionals;
- Respect for other people’s perspectives is paramount in building effective relationships (particularly trust) in mental health;
- Better communication in mental health between all stakeholders;
- Values of openness, honesty and respect between stakeholders prioritised in mental health;
- Carer involvement should not diminish service user wishes.
Other key considerations:

- Strong service user view that information should not be shared without consent in any circumstances;

- A third of service users did not want carers to be given separate time with professionals to discuss their concerns, reporting that the service user should always be present if they are being discussed by professionals and carers;

- In certain circumstances, the definition of ‘carer’ is unclear requiring clarification through policy guidance or the law;

- Information sharing problems relating to the professional role require both system level changes and professional training;

- Advance statements were proposed as a suggested solution.

The carer dataset provided wide ranging views on both the problems of poor information sharing and how ‘positive practice’ can be achieved. We outline below a summary of the main issues raised:

- Carers do not have sufficient information to support them – neither general nor personal information. Mental health services must provide carers with basic information on mental health problems and ways of coping as a carer;

- Carers do not have the skills to manage severe mental illness. A range of services including carer education programmes and peer support groups are required to support and effectively empower carers, supporting their own recovery journey;

- Professionals to provide carers with opportunities to discuss information they have found from a variety of sources and to listen to carer concerns;

- Where professionals cannot share personal information with carers because service user consent has not been provided, a supportive explanation should be provided to prevent confidentiality being perceived as a ‘block’ to professionals engaging with carers;

- The difference between general and personal/sensitive information should be clearly understood by carers in the context of their support role and the views and wishes of the service user;

- Improvements in communication between all stakeholders in mental health and allied services is required to improve the quality of services provided;

- A cultural shift within mental health is required, including the changing of professionals’ attitudes towards working with families. Carers ask for respect of their expertise and knowledge from professionals, and to be listened to;
• Develop collaborative working culture in mental health to support the empowerment of carers.

Professionals also provided views on how to address information sharing dilemmas. The new resource has built these suggested solutions into the learning materials. Positive practice principles:

• Where policies exist they are rated as useful by practitioners – accessible and useful policies / guidance on confidentiality should be widely available to professionals (as well as for service users and carers);

• Service users do not want information shared without their consent but professional recognise there are appropriate circumstances where patient confidentiality should be broken. When patient confidences are broken the reasons for this decision should be shared with the service user at a timely and appropriate meeting;

• Collect and routinely review consent, and use advance agreements to establish what information can be shared with a carer. Professionals may have to spend time explaining to service users why carers ‘need to know’ details about their care and treatment;

• Professionals should be trained in the application of patient confidentiality to address staff’s lack of skills and confidence in working with carers and sharing information effectively;

• Recognition of the carer role by all professionals, with active consideration of the involvement of carers being made ‘from day one’ though actual involvement will be undertaken in consultation with service user;

• Balancing carers’ ‘need to know’ with service user ‘right to privacy’ and honest and open communication of decisions taken;

• Support services should be made available for carers including carer assessments, and general information packs;

• Adopt a collaborative approach in mental health involving all relevant stakeholders (members of mental health profession, family, advocates, service user, support staff).

Other considerations from professionals:

• Professional reluctance to working with carers, that has traditionally been the responsibility of social services, must be addressed if carers are to be effectively supported through appropriate sharing of information;

• In order for professionals to effectively support and involve carers they need sufficient capacity, and recognition of this resource commitment, within their role to enable professionals to better work with carers.
3.6 Discussion

3.6.1 Summary of key findings

The practice survey, follow-up interviews and original data set confirm that information sharing with carers is an important issue for mental health staff and more training is required to improve on current practices. We found among Trusts responding to the survey 31% offer no specific training covering information sharing with carers.

In exploring preferences for how training is delivered, there was strong support for face to face training involving real carers. Tempered against this was also an acknowledgement that barriers to training, including staff time pressures and the cost of bringing groups together for training need to be addressed. The concept of self-paced learning was actively supported in 78% of responding Trusts. From the interviews, we learnt interest in self-paced learning is mixed. Five people firmly supporting face to face formats, 8 identifying self-paced learning (either CDROMS, online web-based packages or both) as the preferred Trust learning format. Information gathering with education experts indicated the importance of blended learning across the NHS, emphasised how critical it was that the learning resource could link to professional development portfolios to provide a motivational ‘carrot’ for learners to take part and the impact achieved by real carer stories.

The original data, and the scoping interviews, provided a draft framework for the content of the resource. Modules needed to cover:

- The importance of consent
- The different types of information – general, personal, personal sensitive
- The importance of communication – and supportive explanations where information can not be shared
- Address the role of carers within meetings
- The use of advance statements
- Practical strategies – when and what to disclose.

The scoping interviews provided notes of caution for the project team. They stressed that training alone will not address the problems of carer involvement and appropriate information sharing. The original research highlighted that a change in culture is required for partnership working between mental health professionals, service users and where appropriate families / significant others (carers) to become ordinary practice. These interviews also acknowledged that the new resource must work with existing training options, complementing local carer strategies, induction programmes and CPA training.
It was clear from the scoping phase, that developing a resource that would become embedded in routine practice was a significant challenge. It was also reassuring to learn from the practice survey that 65% of responding Trusts offered their support to develop new resources to address information sharing with carers.

3.6.2 Limitations

The survey was limited by its brevity and poor response rate. The poor response is a particular challenge because the survey provided the sampling frame for the telephone interviews, and thus any sampling bias is carried forward into that element of the development process as well. There could be a number of explanations for the poor response. Trusts may not have cascaded the survey down to a relevant member of staff, staff who received the survey felt they were unable to answer on behalf of the Trust or the request for information was not dealt with as a priority. Feedback from respondents also revealed how difficult it was to answer accurately for whole staffing groups when learning style is often an individual preference and a Trust has not audited staff to capture this information.

The telephone interviews were carried out across a range of Trusts in England covering rural, urban and inner city communities, and varying sized geographical catchment areas however the sampling pool was limited to Trusts responding to the survey which was only 36%.

3.6.3 Next steps

Information from the three scoping modules was collated to inform the development phase. At the same time a new proposal was submitted to NIHR SDO for resources to change the format from face to face delivery to self-paced learning. Although there was a mixed response towards self-paced learning in the Trusts from practitioners, all the mental health educators approached indicated their Trust or organisation was developing self-paced modules. The project’s focus on producing an easy to use sustainable training programme to supplement existing initiatives within Trusts, including work with carer trainers, lead the team to development of a self-paced learning resource which would be delivered online. The online format was chosen to facilitate the updating of materials over time.
4 Second phase development

This section describes the initial planning and development of the online learning resource, involving further consultation and review before the resource was actually built. The consultation was with NHS Trusts and mental health professionals. The review was of e-learning packages. This phase took place from May to September 2008.

4.1 Objectives

The main objectives of this phase of the project were:

- To recruit two pilot sites to work with the project team on developing the resource;
- To review e-learning packages to identify key features to incorporate into our learning resource;
- To recruit a project partner to build an online learning resource;
- To consult with our target group of mental health professionals, to canvass their views on the issue of confidentiality and information sharing with carers;
- To identify essential learning points for the resource to address and key formatting requirements from the target group of learners to ensure the resource was accessible and engaging.

4.2 Method

The development phase involved a number of components moving the project towards the building of the new training resource (see section 5). The emphasis was on consultation within the development sites and review of e-learning packages to gain a better understanding of e-learning formats.

4.2.1 Development Trusts

During the practice survey phase (see section 3) we asked Trusts to indicate their interest in the project. One Trust had indicated their support to the project prior to submission of the funding proposal. This Trust was dealing with a number of complaints from carers regarding information sharing, and our project was felt to be an important development for them in addressing carer concerns. We followed-up with the Trust post-survey and they indicated continued commitment to the project. The Trust is located in the North of England covering a population of 1.4 million.

To complement this site, we sought to recruit a second Trust from London. Our second development site covers a portion of greater London, both inner city and suburbs spanning eight boroughs with a diverse population of 1.8 million.
In both sites, telephone conference calls with senior managers were held to establish their commitment and outline the next steps required to deliver the project. It was understood that senior leadership in the Trust was crucial if the project was to be successful. Discussions also considered the ethical requirements for the project and ICT considerations.

4.2.2 Ethical review

The project was not designed as a research study. It was a practice development project. Advice from NRES was sought to confirm that ethical review was not required. The project did not meet NRES criteria for research. In the development Trusts advice was sought about which relevant approvals would be required. Project information was reviewed for clinical governance purposes in both sites.

4.2.3 Review of e-learning

The culture of e-learning is evolving across the NHS and in social care settings. The project team reviewed several packages to understand key common features such as the style of writing, use of interactive materials, questions and discussion points to enhance user engagement and general design and layout.

4.2.4 Recruiting a self-paced project partner

The project team prepared a project proposal extension for NIHR SDO in Autumn 2007. At this point we needed to recruit a project partner to build a self-paced learning resource – either as a CDROM or online web-based programme. The steering group were involved in advising on this process and we approached two companies to pitch for the commission. At this stage there was no guarantee that the self-paced learning element of the project would be funded. The pitch was to partner Rethink, the University Swansea and Kings College London to approach NIHR SDO for additional funds to cover the build of self-paced package. Both companies presented their pitch to the steering group on 2nd October 2007. The steering group awarded the work to Minervation, based on their experience of working with consumers to develop resources, and expertise in the mental health field.

4.2.5 Consultation with mental health professionals

A key part of the development phase involved working with staff across the two development sites. Discussion groups were held with 36 participants and telephone interviews were conducted with 13 participants. Participants were drawn from all the key mental health professional groups (psychiatry, nursing, psychology, social work and occupational therapy). The purpose of the discussion groups was threefold:

- To establish the wants and needs of the core target group of mental health professionals, regarding training on the issue of information sharing with carers;
To gather information on participants’ ideas about the most effective format and content of such training;

To test whether ideas about the resource content and format were what the target group wanted and what they thought would be accessible and useful to them and their colleagues. Based on the consultation carried out in the first development phase, and the original project data (see section 2 for overview), the project team had started to design an outline training package.

We worked with a key Trust representative to help with recruitment to the discussion groups and individual interviews in both development Trusts. A convenience sampling technique was adopted with interested professionals volunteering to participate. This sampling technique was used as we wanted to engage with participants who had an interest in this area of work to guide us at this stage. All participants received information in advance about the session (see appendix III).

In the northern site, the Trust representative sent an e-mail to mental health teams asking them to nominate a representative to take part in a discussion group or telephone interview. The Trust representative was asked to ensure that all the main mental health professional groupings were represented and that participants were drawn from both community and acute settings. This was achieved. Participants with a background in psychology (n=1), psychiatry (n=1), nursing (n=3) social work (n=1) and occupational therapy (n=3) took part in two discussion groups. Participants were drawn from acute settings (n=5) and community settings (n=4). Two groups were held in total. Participants provided signed consent forms to take part and the groups were audio-recorded.

In the London site, we again worked with a Trust representative to recruit mental health professionals to take part. The local recruitment process here, however, was different with discussions, three in total, being held with a community mental health team, an acute team and the team managers of all community teams and all acute teams. It was suggested by Trust representatives that operating the groups in this way would provide access to the largest variety of staff, in a timely and efficient manner. These brief sessions took place within team meetings, and participants were not asked for consent to take part and the conversations were not audio-recorded. Again participants with a background in psychology / psychotherapy (n=3), psychiatry (n=3), nursing (n=5 [CPNs], n=14 [senior nurse managers]) social work (n=1) and occupational therapy (n=1) took part in the team discussions.

The groups were facilitated by the project researcher. Information was analysed thematically and the key themes extracted to feed into the build phase.

The telephone interviews that followed up the discussion groups were held with 6 professionals from the London site and 7 from the northern site. The participants had a background in psychology (n=1), psychiatry (n=2), nursing (n=4) social work (n=2) and occupational therapy (n=3) and
community support (n=1). Their work settings were community mental health teams (n=6), in-patient settings (n=4), drug rehabilitation unit (n=1), crisis teams (n=1) and assertive outreach teams (n=1).

Interviews with staff sought to further explore the issues raised in the groups to gain a more in depth overview of the training wants and needs, and opinions on content and format of the core target audience. A semi-structured interview schedule was designed. This covered the general thoughts of participants on the issue of information sharing with carers, current sources of support in the event of information sharing dilemmas arising, experiences of particularly ‘good’ and ‘bad’ training. It also addressed ideas about the content and format of a learning resource to address issues of information sharing with carers (see appendix IV for the full interview schedule).

All interviews were conducted via telephone by the project researcher at a time that was convenient for the mental health professional. All participants were sent an information sheet and a consent form which was returned via fax, post or e-mail, prior to taking part in the interview. Detailed notes were taken by the project researcher and written up upon completion of each interview. Each interview was between 30 and 45 minutes in duration. Interview notes were thematically analysed independently by two project researchers.

4.3 Feedback from the development Trusts

Senior management in the development sites provided a clear steer on the minimum requirements for self-paced learning. There was a clear preference for a web-based resource in both development Trusts. This reflected the overall NHS trajectory of producing more online learning packages, to acknowledge a learning culture in which financial pressures and time constraints means that self-paced online learning modules provide a cost effective means of enhancing learning. We also needed to be able to track learner participation to link the training into personal development portfolios. This required any learning resource to be SCORM (Shareable Content Object Reference Model) compliant.

4.4 Review of e-learning

There is an increasing literature which focuses on the learning needs of professionals working in fast paced environments such as the NHS and the relative merits of different training approaches and mechanisms. The project team both reviewed current e-learning packages and literature relating to learning styles to assist with the development of the new resource (see section 5 for the literature review on learning styles). E-learning is defined as ‘the use of internet technologies to enhance knowledge and performance. E-learning technologies offer learners control over content, learning sequence, pace of learning, time, and often media, allowing them to tailor their experiences to meet their personal learning objectives’ (Ruiz et al, 2006).
In recent times in line with advances in technology and digital resources, the e-learning environment has developed considerably. Organisations such as the NHS have been following a training trajectory which has begun to focus its attention on developing e-learning tools. There have been a number of initiatives within the NHS recently that have begun to promote e-learning as a cost effective means of providing sustainable learning to health professionals. E-learning for health for example, aims to gather e-learning resources to be made freely available to NHS staff (see www.e-lfh.org.uk), while the National Learning Management System and Electronic Staff Record aims to track staff learning for the purposes of professional development. E-learning has been recognised as a cost effective means of producing self-paced training which can be standardised and modified to take account of developments and form part of the blended learning platform. The NHS sponsored e-learning for health collaboration have stated:

‘As one of the world’s largest employers, NHS investment in training must be high quality, efficient and cost-effective. Trainees work in virtually all hospitals in the UK, and are exposed to a widely varied caseload. However, support from consultants and tutors can vary and there is increasing pressure on time and financial resource for learners or trainers to attend local, regional or national teaching sessions’ (www.e-lfh.org.uk).

### 4.4.1 E-learning packages

The consultation indicated that a self-paced online package would be the likely format of the learning resource, thus it was important to review national e-learning packages currently available to health professionals. The purpose of the work was to record the useful features of these resources and to use this to inform the development of the new resource. The main packages are summarised in Table 6.

The review of the current e-learning resources provided a valuable grounding in the common features of e-learning packages. These features were considered individually and adapted to be incorporated appropriately into the build phase of this project (see section 5).
Table 6. Review of e-learning packages

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
<th>Useful Features</th>
</tr>
</thead>
</table>
| UK alliance for e-learning in health         | Database of NHS and Social Care e-learning Resources which denotes status of resources i.e. their launch date and how to access them                                                                                 | -Good lesson menus with clear controls for the user  
-Icons used for controls obviously denote their purpose  
-Very good use of a variety of interactive tools to encourage users to engage e.g. questions, discussion points, reflections  
-Good mix of visual images, written text to appeal to a variety of learning styles                                                                 |
| E-learning for Healthcare (e-LfH)            | e-LfH is a Department of Health Programme in partnership with the NHS and Professional Bodies providing e-learning content free of charge for the training of the NHS workforce across the UK | -Learning objectives clearly stated  
-Clear lesson menus with forward/back controls  
-Pages clearly numbered so that learners can see where they are in lessons  
-Users interact with programmes in a number of ways e.g. by writing in response to questions and clicking correct answers from a selection of multiple choice questions to stimulate thought and reflection  
-Use of a range of features to appeal to different learning styles e.g. sound and visual images  
-Examples of practical dilemmas shown on video to bring issues to life                                                                 |
| National Learning Management System (NLMS)   | The development of the NLMS is a joint initiative between the Department of Health, NHS Connecting for Health, NHS Core Learning Unit, e-LfH and the Electronic Staff Record Programme (ESR) | -Clear lesson menu and controls for user  
-Logical flow of material  
-Good use of visual images  
-Good use of questions to aid reflection throughout course of modules  
-Built using Adobe flash player  
-Broken into module/lesson format with each addressing a key point  
-Quiz at end of module to reinforce learning                                                                                           |
| NHS Core Learning Unit e-learning packages   | The NHS core learning unit contains e-learning packages suitable for staff across a range of health and social care settings. Users are required to register to access resources and learning can be recorded through a tracking system for CPD purposes | -Interactive modules that engage the user  
-Questions in modules to reinforce learning  
-Practical dilemmas mentioned which encourage users to reflect on practice  
-Summaries of key learning points included  
-Good use of interactive features such as video, which helps to break up lessons and maintain the interest of users  
-Registration system to enable learning to be tracked                                                                 |
4.4.2  E-learning for health professionals

There is a developing body of evidence on the effectiveness of e-learning for health professionals. In a randomised control trial Davis et al (2007) for example, compared six e-learning courses to lecture based learning and found that e-learning was as effective for educating medical professionals. E-learning can provide a number of advantages over traditional training models for health professionals. They can be carried out to fit around work load and provide standardised training. Recent reviews of the e-learning literature in diverse medical education contexts reveal similar findings. Chumley-Jones et al (2002) reviewed 76 studies from the medical, nursing, and dental literature on the utility of web based learning. About one-third of the studies evaluated knowledge gains.

Regardless of learning style, there is firm support in the literature for training that incorporates a variety of elements and interactive features, to maximise learning, in favour of traditional didactic models. Ruiz et al. (2006) have contended that e-learning permits greater learner interactivity and promotes learners’ efficiency, motivation, cognitive effectiveness, and flexibility of learning style. Learning is a deeply personal experience: we learn because we want to learn. By enabling learners to be more active participants, a well-designed e-learning experience can motivate them to become more engaged with the content. They argue further that such interactive learning that shifts the focus from a passive, teacher-centered model to one that is active and learner centred, offers a stronger learning stimulus. Interactivity helps to maintain the learner’s interest and provides a means for individual practice and reinforcement.

Evidence suggests that e-learning is more efficient because learners gain knowledge, skills, and attitudes faster than through traditional instructor-led methods. This efficiency is likely to translate into improved motivation and performance. Multimedia e-learning offers learners the flexibility to select from a large menu of media options to accommodate their diverse learning styles (Clark, 2002).

4.5 Consultation data: discussion groups

Five groups were held in total, although the three team meetings in London were only brief sessions. The groups were broad discussions which examined the relevance of the topic for participants. The groups also focused on practical examples of the challenges faced on the topic by participants. The groups also examined the topics to be covered by the learning resource and the most appropriate format for the package.

4.5.1  Common information sharing dilemmas

The participants across each group felt the topic – information sharing with carers - was a relevant issue that should be addressed.
‘Yes, it’s definitely something that comes up a lot for us, particularly with newer staff so yeah I do think there’s a need for better training on it’ (ID 14, Team Manager)

‘I think a lot of people do worry about complaints and to be honest I don’t always know when I should and shouldn’t, it’s really difficult to balance the needs of the carers and patients so it would be good to know what you can and can’t do really’ (ID 21, CPN)

It was acknowledged that the issue of information sharing with carers was hugely complex and that a lot of mental health professionals, particularly newly qualified staff but others too, were unclear about what to do when dilemmas arose.

‘It’s more a problem with the inpatient team ... because we get people when they’re acutely unwell and we tend to have fluctuating levels and one day they’ll say yes you can speak to my carer and the next day they’ll say no you can’t and it becomes really complicated and I think the carers themselves feel that we’re being quite contradictory, that we’re being inconsistent in talking to them really’ (ID 47, Psychiatrist)

The groups also provided real examples of the dilemmas staff have faced in practice. For example one participant spoke about the issue of abuse and what to do if a carer was accused of abuse but there was no proof.

‘It’s a really difficult situation, e.g. if a patient alleges abuse but the carer denies it and then you’ve got the risk element while also trying to think about the patient and the carer’s needs’ (ID 35, Psychologist)

Another situation that was spoken about frequently was when carers felt that they had a right to information e.g. when their son or daughter was unwell but the service user did not want them involved in any way.

‘When a carer phones up and the person is unwell or that something has happened and they want to know what’s going on but you know that the patient doesn’t want them involved it can be very hard to balance all of those interests and decide what’s the best thing to do’. (ID 38, Social Worker)

We also heard of difficulties in managing meetings where a carer wants to be involved and the service users does not want them included in a discussion.

‘I can think of a couple of difficult situations recently where we’ve had carers who’ve refused to leave while we’ve been trying to talk to the service user and they have made the point – this is my house, this is my front room, I’m not going... home visits. There’s a big control issue when we have delved into why they wanted to stay ... which is maybe why they’re not very well at the moment because of the control issues. That’s the converse really of wanting to share with carers sometimes you don’t want to. I always try and see people for at least part of the assessment on their own’ (ID46, Psychiatrist)
Another challenge related to the age of the service user, and particular dilemmas when dealing with the parents of young people.

‘There’s quite often issues when we get young people in because there’s that age where well they’re still my children but they’re adults as well at 16 and their own right to be able to say that they don’t want their information sharing with their families. I found that very difficult sometimes. And I think that the staff in general find it difficult because they don’t understand what they can information share and what they can’t information share, they don’t understand about the risk elements’ (ID 44, Occupational Therapist)

There can also be problems receiving new sensitive information provided by the carer. Accepting information from carers and writing this in the notes, can cause concern because at a later date if the service user asked to see notes it could impact on relationships between staff and service user, or service user and carer.

4.5.2 Advice on developing the new resource

Participants across the groups had ideas on what the new resource should contain and how to ensure it was useful and therefore used. Firstly there was consensus that both information and practical advice were required.

‘I think it would be good to almost have a ‘one stop shop’ where you could get lots of information if you needed it, you know obviously not go through it all but just have it there for reference so maybe best practice things and practical tips’ (ID27, Occupational Therapist)

Considering the format for the resource in more detail the following advice was provided:

- The training needs to be emotive, using real stories.
  ‘I think hearing personal stories and real life examples are always a good idea, it connects you to the situation’ (ID 16, Community Mental Health Team Manager)

- The training should ask participants to consider themselves in this position
  ‘And I think personally that personal stories are really powerful and often the case managers often have their own kids and if you say I mean a lot of the people we work with can be 16, 17 if you imagine your child suddenly started hearing voices and doing all these things wouldn’t you want to know what was happening and I think that’s much more powerful than you know, if you put it in your own family you sort of, it hits home really just how distressing it must be for the family members’ (ID49, Occupational Therapist)

- The training should help bring the subject alive because many staff are at saturation point reading documents.
- The training should focus on what people can do, rather than what they cannot – making it practical and helpful.
‘I think what we really need is more information on what to do, if you find yourself in a situation where you’re not sure’ (ID28, Psychologist)

- Participants emphasised the need to explain to mental health professionals that it is possible to work with the family without the service user’s consent, within certain boundaries.
- Participants also believed that the resource should help mental health professionals to understand the boundaries of information sharing.

‘I think a lot of people do worry about complaints and to be honest I don’t always know when I should and shouldn’t, it’s really difficult to balance the needs of the carers and patients so it would be good to know what you can and can’t do really’’ (ID 26, CPN)

- The training should cover legal information and summarise information sharing principles.

‘I think it’s important to know about the legal aspects as well and the basic fundamental principles, perhaps not in great depth but at least to have an overview’ (ID15, Team Manager).

- Sheets containing tips for care co-ordinators and ward staff on re-visiting consent issues would be useful.

‘I was just thinking about maybe some tips for the care coordinator or nurse about how to negotiate that back to the service user and sort of look at the consequences of not sharing information and just try and get that conversation developed because I think staff sometimes go ok then and leave it at that’ (ID 45, Senior Ward Nurse)

- There was an acknowledgement that there was sometimes a need to help staff to address their attitudes to carers, as this can form part of the problem.

‘Because very often carers get upset because of the attitude that we take rather than what we’re saying’ (ID 48, Senior Nurse)

- Participants also believed that the resource could address the problems of identifying who the carer actually is in practice.
- Participants also raised the issue of acknowledging circumstances when staff should not engage with the carer e.g. in the minority of cases where the carer is exploitative.
- There was a desire amongst participants to ensure that the resource can link individual learning with group discussions to enhance learning within teams.

A number of participants raised the issue that this was an extremely complex area and one participant stated that he did not believe that training was enough to tackle the issue:
‘It’s a hugely complex issue and I don’t think training alone will make a huge difference, you need practice, experience, the advice of colleagues etc.’ (ID 40, Ward Manager)

It was extremely important to take this perspective into account and to acknowledge that producing a learning package in isolation would not provide a solution to this complex issue. Rather, it was envisaged that the training materials produced would fit within a framework and form part of a jigsaw of measures to address the issues. This links to similar feedback received in the interviews reported in section 3.

Finally, participants reminded the research team that training had to be engaging and interactive. Many had previous experience of training which they felt was not worthwhile. They also reminded the team that without sufficient time being allocated to the training initiative, it would not succeed in improving practice.

‘I think you need to make it interesting for people, we’ve all sat through training where we’ve wished we were somewhere else so it’s got to keep your interest’ (ID 27, Psychiatrist)

4.6 Consultation data: interviews

From our 13 interviews, six professionals described the issue of information sharing with carers as an issue or problem. Where it was not described as a problem, this was because the participants felt confident they were following best practice and appropriate policies or their role did not involve face to face contact with carers. For example, a social worker explained how when clients do not want information shared with carers she tells the carer she appreciates the situation they are in but she cannot impart information to them (ID 6, social worker). In an assertive outreach team the CPN explained how information sharing was not an issue, trust policies are adhered to, the client’s wishes are respected and for legal matters the Trust solicitor is consulted (ID 8, CPN).

Confidence emerged as an important theme in the interviews. This was mainly expressed as confidence in one’s ability to judge appropriately how to share information, or lack of confidence in dealing with carer requests.

‘Sharing information with carers is a big issue in lots of ways. The issues are very difficult and problems arise all the time, there are lots of times when I’m not sure what to do’ (ID 3, Specialist Registrar in acute unit)

‘We follow the OT code of conduct. This states client confidentiality unless there is a risk. However, information sharing is not so clear-cut, and there are still difficult situations that arise when health professionals are unsure of how to act’ (ID 4, OT working on in-patient ward)

‘In general I don’t always know what I should be doing in terms of information sharing’ (ID 13, Trainee psychiatrist working in an inpatient setting)
4.6.1 **Content for the new resource: participant views**

The interviews were an important source of information about when and where information sharing dilemmas are most difficult, to inform the building of the resource. As a general point the demand was for a practical resource:

*I think we need a pragmatic approach to training and the inclusion of suggestions as to how to deal with particular situations.* (ID 10, clinical psychologist working in a CMHT)

When asked about the standards currently adhered to when dealing with issues of confidentiality and information sharing with carers, a number of participants expressed the view that there was a lack of practical guidance on the issue. A CPN working in a community setting mentioned that as a rule he tried to adhere to Trust policies and data protection guidelines but that these were not always helpful when information sharing dilemmas arose:

*The Trust policies and Data Protection Act are adhered to. However, this can be difficult because it is not clear how much information you can divulge as a health professional* (ID 1, CPN)

Similarly a specialist registrar working in an acute setting mentioned that the Trust and General Medical Council guidance that she adhered to focused on confidentiality but did not have enough emphasis on information sharing.

*The Trust policies and GMC policies are adhered to. The only issue that this covers well is confidentiality. There is not enough information about information sharing* (ID 3, Specialist registrar working in an acute setting)

Eleven participants (out of 13) reported that they would find it helpful to be able to access strategies on how to deal with real life information sharing dilemmas through case studies. They emphasised that these should not be too straightforward as dilemmas occur when cases are complex. Ten participants wanted the training to address legal aspects of information sharing.

In terms of practical examples of information sharing dilemmas, six people described eleven difficult situations. These were:

1. When a service user is not willing to consent to information sharing and the family are concerned. Particularly difficult when service user is unwell, which is often when the family are most keen to have information.

2. When a service user’s relatives phone up because they are worried about the service user’s health. As a health professional you are concerned about the service user but you do not know what the carer does and does not know about the service user.

3. When two members of the same family are being treated in the same place, as a health professionals it is important to be very clear about which person the carer is referring to in conversations.
4. It is difficult when patients talk about being mistreated by their carers. It is hard to know if the information is true because the patient is unwell. Yet it is important to protect the patient. However, it is also important to maintain a good relationship with the carer.

5. It is hard when the information you have on the service user is different to what the carer is providing. When you know something that the carer declares is not true.

6. Difficult when you feel bullied by the family. When they are making decisions for a service user and putting pressure on them but you are cautious of their motivations and what are the best interests for the service user. How to deal with the family in meetings.

7. It is awkward when the carer provides new information on the service user that you do not know. You cannot disclose this to the service user.

8. When a carer wants to see the service user’s notes but you know the service user does not want information shared. When the carer will not accept this decision and becomes aggressive.

9. When a service user does not want information shared with the carer but the decision being discussed actually involves the carer. For example there was a meeting to discuss discharge home, and service user did not want the carer involved but discharge was to the family home. Knowing whose position to honour is a challenge.

10. When a service users’ circumstances change, such as becoming more independent, but the family – parents – continue to ‘take over’. It is hard to handle this delicate situation, putting service user wishes first but also recognising the parents have needs too.

11. When parents do not share vital information with the team that is relevant to the case and you hear it from the service user instead. Knowing how to deal with the family without breaking confidences. (This is in effect the reverse of point 7 above).

4.6.2 Format of the new resource: participant views

The final part of the interviews asked about how the training should be delivered. Participants specified that they wished the format to be engaging and interactive. The key elements identified were:

- All staff need to be trained to the same level (n=3)
- Different levels required – but for all to work through (n=3)
- It should be interactive (n=8)
- It should promote discussion (n=6)
- It should Include a quiz or multiple choice questions (n=2)
- It should link to CPD by providing a certificate (n=1)
- It should include a follow-up element (n=1)
- It should contain video material/DVD (n=9)

‘Case studies and a multimedia element would be useful and clips of people talking would help to hold the attention of those using the programme.’ (ID 10: clinical psychologist working in CMHT)

‘A variety of common and rarer case studies should be covered. It is always helpful to know how others deal with situations’ (ID 5, Crisis Practitioner)

‘Case studies would be beneficial for the team to learn about information sharing with carers. This would have to be done carefully because sharing information with carers is a complex topic’ (ID 6, Social Worker)

When the concept of e-learning was introduced, there was a mixed response. Five people felt e-learning was useful, although two qualified it would not be well received by all staff. Six people felt e-learning would not work, two did not comment.

‘It is hard to motivate yourself with e-learning. The mind goes blank when staring at text on the screen. If training is in the form of e-learning, the material must be short and punchy’. (ID 1, CPN)

‘E-learning would be great as long as there is group discussion afterwards to reflect on learning’ (ID 9, OT on in-patient ward)

Cascade learning was also presented as a practical solution to overcome time constraints of releasing staff for training. Six people felt this was a useful strategy but seven disagreed feeling everyone needs to learn these fundamental skills.

‘I think it would be a good idea to train one person up in the team who then goes to disseminate information to the rest of the team and get discussions going on the issues’ (ID 7, Ward Manager)

‘The training package should target the whole team. The whole team needs to be reading from the same page. It wouldn’t work to have a ‘champion’ who disseminates the information. If only one person on the team is trained, there are no others to verify what is good and bad practice. Also, there is not enough time for a ‘champion’ to inform the rest of the team about the particulars of the training’ (ID 9, OT working in an acute setting)

Other participants felt that regardless of how training on the topic was presented, it was important to promote shared learning, interaction on the topic and discussions amongst teams.

‘Discussions are the most effective method of training. Interaction is important for learning. The training should be in the format of an introduction, followed by discussions, group work and presentations’ (ID 8, CPN)
‘Having audio and video features to make the learning package interactive is a good idea’ (ID 7, Ward Manager)

A number of participants emphasised the need for flexibility in training. This is a finding that fits closely with the findings from the first phase development research. Participants spoke about busy work schedules and the desire to be able to ‘dip in and out’ of learning as their schedules allowed.

4.7 Discussion

4.7.1 Summary of key findings

The development phase provided the project team with a clear steer on how the new training resource should be developed. It needed a strong information section providing the ‘one-stop’ resource of practical tips and guidance. From the review of e-learning packages, as well as feedback from staff, the inclusion of an interactive course was also prioritised. This would ensure that the resource would be:

- Emotive
- Interesting
- Based on real case studies
- Engage with a range of learning styles
- Promote reflective thinking

The development Trusts emphasised the importance of the inclusion of requirements such as producing a record of learning for professional development purposes, SCORM compliant and accessibility guidance compliant.

Based on the findings from consultation with mental health professionals it was decided to build a resource that would contain information on the principles and legal aspects of confidentiality and information sharing and good practice strategies. This information would be drawn from the original NIHR SDO research. It was also decided that real life dilemmas had to be used to illustrate practical strategies for dealing with information sharing dilemmas. Throughout the resource there would be a firm emphasis on a professional style of language, interactive features and a mix of video, audio and text to appeal to a range of learning styles. The pitch was to a range of professionals. The resource was developed for use by individuals, but team discussion would be encouraged as a way of using the materials in groups.

The data from the consultation also provided some scenario outlines to be used in the development of video and audio clips. The suggestions that we carried forward were:
- A carer telephones asking for information, and the service user has not given consent to speak to the family;
- Where the carer is suspected of abuse and contacts the team for information;
- A carer wants to attend a meeting with the care team and service user, but the service user does not consent to their presence.

The consultation interviews alerted the team to potential problems with an e-learning resource: learner resistance. There were a number of mental health professionals who felt e-learning as a training mechanism was unhelpful and others who felt it was particularly unsuitable for this topic – information sharing with carers. This resistance could impact on implementation, and work with NHS Trusts to promote the benefits of the resource will need to be carefully planned.

### 4.7.2 Limitations

The discussion groups did not employ similar formats in both development sites. In one, specific discussion groups with mixed groups of professionals drawn from across the Trust were convened. In the second, team meetings were used with discussion among colleagues encouraged. This approach was used to work with Trusts in the most efficient and timely manner possible but a consistent approach in both sites would have made comparisons between sites easier to identify.

### 4.7.3 Next steps

To use all the collected information and the skills of our web developer partners to create an engaging and informative e-learning tool.
5 Building the resource

This section outlines the building of the learning resource which took place between October 2008 and July 2009. It might be helpful to view the online resource at this point, if you have not already done so. The pilot resource can be found at: http://rethink.minervation.net. The fully revised resource can be accessed at www.carersandconfidentiality.org.uk.

5.1 Objectives

The main objectives of this phase were to:

- Build an online learning resource to meet the learning needs of mental health professionals on the issue of carers, confidentiality and information sharing;
- Develop and design content and format to be accessible, engaging and grounded in real life practice.

5.2 Method

The resource was built in stages. The technical elements were led by the Minervation team and the content was developed by the project research team based at Rethink, with assistance from the steering group, King’s College London and University of Swansea. An overview of the build phase is provided in figure 5. The main website sections and the interactive course were developed simultaneously with input from the steering group, external experts and Rethink staff.

The project team developed a set of criteria to adhere to when building the resource. These are outlined in Table 7. The build phase also drew on an understanding of learning styles and preferences.
### Table 7. Criteria for developing the resource

<table>
<thead>
<tr>
<th>Content criteria – Include:</th>
<th>Format criteria – The resource:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Key principles of confidentiality</td>
<td>• Should be online to allow it to be ‘future proof’</td>
</tr>
<tr>
<td>• Best practice strategies</td>
<td>• Must be interactive to engage learners’ interest</td>
</tr>
<tr>
<td>• Useful resources on working with carers</td>
<td>• Must adhere to accessibility guidelines and be built to be</td>
</tr>
<tr>
<td>• Resources to share with carers</td>
<td>accessible to as wide a range of mental health professionals</td>
</tr>
<tr>
<td>• Information on legislation and the codes of practice underlying confidentiality</td>
<td>• Must be easy to navigate</td>
</tr>
<tr>
<td>• Practical steps to be taken when consent to share information with carers is withheld</td>
<td>• Must encourage reflection and connection to own practice</td>
</tr>
<tr>
<td>• Details on good practice to adhere to when consent to share information with carers is given</td>
<td>• Must contain a variety of multimedia elements e.g. sound, video</td>
</tr>
<tr>
<td>• Information on practical ways to support carers</td>
<td>• Must contain a variety of methods to engage learners and appeal to varying learning styles</td>
</tr>
<tr>
<td>• Definitions of key terms</td>
<td>• Must contain a quiz to test learning</td>
</tr>
<tr>
<td></td>
<td>• Must contain a mechanism by which to link to continuing professional development or staff records</td>
</tr>
<tr>
<td></td>
<td>• Must be SCORM compliant</td>
</tr>
</tbody>
</table>
Figure 5.  The building of the information sharing with carers resource

Consultation with Mental Health Professionals

Original NIHR SDO research report (2006)

Consultation with carers and other stakeholders including learning specialists

BUILD PHASE I

Information Architecture

Content: main web site sections and interactive

BUILD PHASE II

Mock up resource ‘shell’ built by Minervation

BUILD PHASE III

MAIN WEB SITE: INFORMATION PAGES

Draft content for information pages, collate download material and links to other

Edit web pages based on feedback

Cross reference main pages to

INTERACTIVE COURSE

Draft film scripts

Script refinement

Final scripts agreed

Plan lesson elements

Draft lessons

Casting actors

Filming / recording

Revise lessons

Editing

Integrate lessons elements with video and audio

Segment the film clips to build the

BUILD PHASE IV

BUILD PHASE V

PILOT THE RESOURCE (see Section 6)
5.2.1 Models of learning

Learning styles is a term used to describe the attitudes and behaviours, which determine an individual's preferred way of learning. Most people are not aware of their learning style preferences (Honey & Mumford, 1992). Several models have been proposed to categorise learners. For example, Soloman and Felder (O'Neill, 2003) developed both a model and an 'Index of Learning Styles'. The model divides learning styles into four categories:

- Active And Reflective Learners
- Sensing And Intuitive Learners
- Visual And Verbal Learners
- Sequential And Global Learners

Honey and Mumford (1992), two British psychologists developed a Learning Styles Questionnaire, which categorised people by their preferred learning styles into:

- **ACTIVISTS**: involve themselves fully and without bias in new learning experiences. They are open-minded, and tend to actively engage.
- **REFLECTORS**: like to stand back and ponder experiences and observe them from many different perspectives. They collect data and prefer to think about it thoroughly before reaching conclusions.
- **THEORISTS**: adapt and integrate observations into complex but logically sound theories. They think problems through in a vertical, step by step, logical manner.
- **PRAGMATISTS**: are keen to try out ideas, theories and techniques to see if they work in practice. They positively search out new ideas and take the first opportunity to experiment with applications. They tend to be impatient with ruminating and open-ended discussions.

Learners may change learning styles depending on factors such as environment and constraints placed on training programmes. One of the most common and widely-used categorisations of the various types of learning styles is Fleming's (2001) VARK model which expanded upon earlier neurolinguistic programming VAK models. This model categorises learners as visual, auditory, reading/writing preference or kinaesthetic learners, or a combination of elements of all four (VARK model). Fleming claimed that visual learners have a preference for seeing (think in pictures; visual aids such as overhead slides, diagrams, handouts, etc.). Auditory learners best learn through listening (lectures, discussions, tapes, etc.). Tactile / kinesthetic learners prefer to learn via experience - moving, touching, and doing (active exploration of the world; science projects; experiments, etc.). Its use in pedagogy allows trainers to prepare programmes that address these areas. It is suggested that most people will have elements of each of these learning types. Thus, in order to build an effective learning package it is important to include a variety of techniques.
e.g. auditory, reading, interactive and visual elements to cater to as wide a variety of learning styles as possible.

### 5.3 Development of main website sections

Designing and writing content for an e-learning resource requires a specific layout, easy to access style of writing and interactive features (Ruiz, 2006). The team set about collating existing materials and drafting new content for the main website sections. All the materials had to be simplified for the new resource. A layered approach was to be used, with links to detailed documents provided for learners wanting more information. We knew from the consultation stages that busy learners need summarised content that can quickly answer their questions, with links to more detail where appropriate. Thus the main website sections aimed to offer synthesised and summarised information, as well as providing a gateway to further detail if desired.

#### 5.3.1. Information architecture

Information architecture is defined as the art and science of organising and labeling websites, intranets, online communities and software to support usability\(^2\). In order to ensure that the main website sections were accessible to learners, it was important that the content was arranged within a suitable information architecture. The project partners Minervation played a key role in the organisation of this content to ensure that it was accessible and clearly navigable. This part of the development process was also subject to usability testing, as detailed in section 6 of the report.

The information was originally organised into a number of headings each with a large number of subsections. However, it was clear that this was not workable in a website format. In designing websites the learners need to reach the information they seek quickly to maintain their interest. In order to do this it is important to restrict the number of levels and layers within a website to ensure that they do not spend a long time searching.

To ensure that that information architecture of the main website sections was suitable for learners, a range of taxonomies were tested informally with the steering group and network of mental health professionals. Thus, different mock ups to test different taxonomies for the site were drawn up and tested for coherence. This was an iterative process.

All the information was finally organised under three main headings: 1) Working with carers, 2) Information sharing principles and 3) Good practice strategies.

These taxonomies were those which fitted best with the content that had been collated from the original NIHR SDO report as well as the content developed and gathered as a result of the scoping and development phases.

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5.3.2 Accessibility

In order to ensure that the site was accessible to all, strict accessibility guidelines were adhered to and the entire website was built to comply with the W3C Web Accessibility Initiative standards. (W3C Web Accessibility Initiative: http://www.w3.org/WAI/).

The site was also built to be SCORM compliant. This is the standard necessary for the resource to be integrated into other e-learning management systems such as the NHS sponsored National Learning Management System. As more Trusts begin to adopt the electronic staff record (ESR) system as standard, we were eager to ensure that the website would be compatible with this and continue to be fit for purpose in the future.

5.4 Interactive course development

One of the main points that emerged from consultation with NHS Trusts and mental health professionals was a desire for interactive learning to form a part of the resource. If e-learning was to be successful it had to be engaging and interactive, linking into real clinical dilemmas and connecting staff with issues that affect carers. A number of mental health professionals commented on the fact that training they had experienced in the past (both face to face and online) worked best and was most effective for them when it contained interactive elements. This approach is supported by the education literature which suggests that learners are most likely to retain information and practice points, if they are presented in an interactive and engaging format (e.g. Davis et al., 2007).

5.4.1 Course aims

The aim was to design the interactive course to perform two functions:

1) To illustrate key information sharing principles;

2) To demonstrate information sharing dilemmas and potential strategies to deal with them.

The interactive course component was designed to comprise of nine 'lessons'. Each lesson would demonstrate either an information sharing principle, or an information sharing dilemma based on real life scenarios, with associated practical strategies. The interactive course was developed by the project team and Minervation with expert input from Rethink’s Workforce Development Team, National Information and Advice Service and the project steering group.

5.4.2 Considerations in planning an interactive course

In planning the course the project team had to consider the following issues:
5.4.3 Accessibility

The course was designed to run using the Adobe Flash player. This is a freely available software package that allows developers to add multimedia content and interactivity to web pages. Flash comes as standard with the majority of modern computers and can also be downloaded free of charge for those who do not have it.

5.4.4 Timing

The issue of mental health professionals having insufficient time to take part in protracted training sessions was emphasised in the consultation stages. Therefore, we set out to design the interactive course so that it would be flexible and could be completed as time allowed. Each lesson was designed to take no more than 20 minutes to complete and learners could save their work as they moved through the course completing as many lessons as they wished at a time. The option to discuss material in team meetings would also be promoted.

5.5 Composition of interactive course

It was decided to develop nine lessons in total. This number of lessons was chosen as it would ensure that learners would take a maximum of three hours to complete all lessons and it provided the project with sufficient opportunity to illustrate a range of information sharing dilemmas and information sharing principles.

5.5.1 Development of case studies for filming with carers

Material from the original NIHR SDO research provided a starting point for drafting the scenarios, as well as consultation with carers. The key aim in developing the scenarios was that they would be based on real life practice and present clinically relevant and challenging scenarios.

A group of carers (n=5) were consulted formally through the use of a discussion group, to ground the interactive course in ‘real’ information sharing dilemmas. This updated information was already available in the original NIHR SDO report. The consultation captured the carer experience of information sharing and the impact it had on them, and the service users they supported. It also established the key points that carers felt were important for health professionals to understand, to ensure a positive and inclusive working relationship with carers, for the benefit of all. This was the only formal consultation with carers in this project.

5.5.2 Essential learning points

'It was just terrible, it was like coming up against a brick wall, they just said they couldn’t tell me anything because of confidentiality, so I spent the
night sitting up with her [her daughter] not knowing what to do’ (ID 3, carer)

From the discussion with carers, there were a number of ‘essential learning points’ identified that mental health professionals should be made aware of to make the information sharing process easier for all parties. The main points are detailed below:

- It does not break patient confidentiality to speak to the carer in terms of ‘general information’
- The use of an advance statement of the service user’s wishes can be of benefit to all when the service user is unwell
- It does not break patient confidentiality to listen to information provided by the carer
- Informed consent should be seen as a process. A service user with a fluctuating condition may well change their mind about this and the issue should be revisited regularly
- It is important to know the difference between different types of information (e.g. general, personal, sensitive)
- It is important to acknowledge the key role that carers play in many service users’ lives and to see them as a ‘partner in care’ and a useful source of information to benefit the service user’s wellbeing
- It is important to offer/signpost carers to alternative means of support if the health professional is not in a position to do this. Carers can find it difficult to adjust to changing circumstances in the lives of those they care for and the support of local carers’ groups/carer support workers may help.

These are similar to the summary points emerging from the original NIHR SDO research report provided in section 3 from service users, carers and mental health professionals.

5.5.3 Examples from carers

The carers who took part in the discussion group put forward a number of their own experiences, which were subsequently modified to be made into scenarios for the lessons. These examples are outlined here:

Example 1: A carer was excluded from the service user’s CPA meeting even though the service user had stated that they were happy to have general information shared with the carer. Lesson 1 was based on this experience.

Example 2: A carer spoke of her daughter arriving at home one night when she was supposed to be in an inpatient unit. When she phoned the ward, the health professional she spoke to refused to give her any information. Lesson 8 was based on this experience.

Example 3: A number of carers spoke about a misunderstanding of the issue of ‘informed consent’ amongst mental health professionals. They also
spoke about the confusion that existed around accepting information about a service user from a carer. These examples helped to form the basis of the scenarios include in Lessons 3 and 9.

The material provided by the carers was combined with information collected in section 4 from mental health professionals, to structure the lesson scenarios.

5.5.4 Refining of scenarios

The ideas for lessons were taken by the project team and developed. A steering group meeting was convened to discuss these scenarios, both to expand on the topic and ensure each contained information that would challenge learners.

The project team made every effort to include a range of scenarios. They ensured that scenarios took place in both community and acute settings, that service users, carers and health professionals represented diversity in terms of ethnicity and background. Scenarios were also devised to include mental health professionals from a range of professional backgrounds (psychiatry, social work, psychology and nursing). The final list of lessons are shown in Table 8.

5.5.5 Development of scripts, filming and editing

Having developed the scenarios, the next step was to script, film and edit to create the interactive course. This was a time intensive process.

5.5.6 Scripting

The project team initially produced draft scripts for the nine scenarios. The development of the scripts was an iterative process, with suggestions and recommendations implemented before further consultation (see appendix V for an example). The steering group were integral in the scripting of case studies, working on the scripts in small groups as part of one steering group meeting and commenting in detail when a project researcher met with them in their own practice setting. This involved carers, a psychiatrist, a psychologist, a carer support worker and social worker. Two Rethink carers and carer support workers, as well as mental health professionals in the development sites reviewed the scripts and suggested modifications.

SeeFood, the production company commissioned to produce the film clips for the lessons, reviewed the scripts in detail. They assessed the dialogue with a particular view to ensuring that it was clear and true to life. They also ensured that it was suitable for filming and complied with all the necessary production requirements. All of the feedback from these sources was incorporated into the final scripts.
### Table 8. Lessons for the interactive course

<table>
<thead>
<tr>
<th>Lesson</th>
<th>Theme</th>
<th>Aim</th>
<th>Source of idea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesson 1</td>
<td>Different types of information</td>
<td>To illustrate the different types of information sharing: general, personal and personal sensitive</td>
<td>Carer’s experience and mental health professional</td>
</tr>
<tr>
<td>Lesson 2</td>
<td>Information sharing with fluctuating condition</td>
<td>To illustrate the importance of advance directives and ways to support carers when a service user changes their mind about sharing information during a fluctuating condition</td>
<td>Steering group and mental health professional</td>
</tr>
<tr>
<td>Lesson 3</td>
<td>Consent as a process</td>
<td>To illustrate the principle that consent to sharing information should be seen as an ongoing process to be revisited often and not as a one off event</td>
<td>Carer’s experience and mental health professional</td>
</tr>
<tr>
<td>Lesson 4</td>
<td>Possible risk to service user</td>
<td>To illustrate strategies to use when consent to share information has been given but there is a suspicion of risk to the service user from the carer</td>
<td>Steering group and mental health professional</td>
</tr>
<tr>
<td>Lesson 5</td>
<td>Uncertainty about levels of involvement</td>
<td>To illustrate the dilemma about uncertainties that arise when one is unsure who the carer is and what their relationship to the service user is e.g. in an apparently transient boyfriend/girlfriend relationship</td>
<td>Steering group and mental health professional</td>
</tr>
<tr>
<td>Lesson 6</td>
<td>Carer adjusting to changing circumstances</td>
<td>To illustrate the needs of a carer for information as circumstances change e.g. as a service user recovers and wants less involvement from their carer</td>
<td>Steering group and mental health professional</td>
</tr>
<tr>
<td>Lesson 7</td>
<td>Carer concerns about changing circumstances</td>
<td>To illustrate the dilemma of working with a new carer and their need for information to care for a service user who is reluctant to have them involved in any way</td>
<td>Steering group and mental health professional</td>
</tr>
<tr>
<td>Lesson 8</td>
<td>Discharge from hospital</td>
<td>To illustrate the information needs of carers and practical strategies to use when an unexpected event such as a patient leaving hospital unexpectedly occurs</td>
<td>Carer’s experience and mental health professional</td>
</tr>
<tr>
<td>Lesson 9</td>
<td>Carers sharing information with health professionals</td>
<td>To illustrate the idea of the carer’s right to confidentiality and the dilemma that arises when a carer provides information to the care team and asks them not to share it with the service user</td>
<td>Carer’s experience</td>
</tr>
</tbody>
</table>
5.5.7 Casting

In order to reduce costs an ensemble cast was employed, whereby each actor would play a number of roles. Casting took place over a day, when at least four potential actors read for each role. In consultation with the production company a decision was made on the most appropriate actor for each role. Actors from a variety of ethnic backgrounds and across the age range were cast to ensure representativeness in the characters.

5.5.8 Filming

Following the casting of the actors, the next step was to identify suitable locations for the filming of the scenarios. We wanted to film scenarios in a number of locations to reflect both community and acute settings.

It was decided to hire an external location to film a number of home scenes and the other scenes would be filmed within Rethink’s main office building. These locations would be dressed with the use of props to look like clinical locations.

The preparation of these locations and exploration of the logistics of filming was conducted by the project team in collaboration with the production company over a number of weeks. Prior to the filming taking place, community and acute health care settings were examined to ensure that accurate signage and other props could be ordered to replicate these locations. In consultation with the production team, the dress of mental health professionals was examined to ensure that the costumes to be worn by actors would accurately reflect the dress of real mental health professionals.

5.5.9 Shooting of scenes

The filming of scenarios took place over three long days in April 2009. Each scene was rehearsed and then filmed from a number of different angles at least four times. A carer consultant who was familiar with the scenarios and scripts was present for the filming, to ensure their authenticity and advise on the tone and acting of each scene. A member of the project team was present at all times.

5.5.10 Editing into short films

Once the scenes had been filmed the next step was to edit the clips into short films to ensure that the best representation of each scene was used in the lessons. This was an iterative process where Rethink’s research team worked with SeeFood to decide on the best clips to use in each of the nine short films. It was important that the short films contained examples of poor practice as well as positive practice, and that they were realistic, engaging and factually correct.
5.6 Building the interactive course

The final phase, after the lesson development and short films were completed, was to actually build the interactive course and link it to the main information sections of the website. Minervation and the Rethink project team worked closely on the lesson build, mindful of the review of e-learning packages conducted in the development phase to ensure that the effective features that had been noted were included. The design was a crucial phase in the project because the resource would not be able to change substantially after the build was complete. To view the piloted resource please visit: http://rethink.minervation.net/

5.6.1 Design of lessons

There are eight factors to consider within the design process for the interactive course. These are outlined below.

5.6.2 Storyboards

In order to begin to work on the layout of the lessons, the project team in collaboration with Minervation designed 'story boards' for each lesson. This mapped out on paper the layout of the lessons, the path that learners would follow through them and the ‘transitions’ that would take the learner from one lesson step to the next.

5.6.3 Registration

In order to allow learners to track their learning, save their work, take a quiz at the end of the course and receive a certificate of completion for the purposes of professional development via e-mail, it was decided to set up a registration system. This system would require learners to enter their email address and then login to the interactive course using a password that would be e-mailed to their address.

5.6.4 Colours and layout

The Rethink branding guidelines were adhered to in the choice of colours to be used in the website. In agreement with the features identified as ‘excellent’ in the review of e-learning packages (section 4) the project team decided that comprehensive layout and use of mental health practitioner language would be used to appeal to the target audience.

5.6.5 Building ‘mock up’ lessons

Building on the original lesson story boards, Minervation in consultation with the project team began to build mock up lessons. These were built using Adobe Flash Player.
5.6.6 Navigation through lessons

There was extensive discussion and informal testing on lesson navigation. The technical aspects of design for this element are complex. It was decided that learners accessing the lesson for the first time would be able to navigate back through the screens they had already seen but not skip forward. This was to ensure that learners did not ‘rush forward’ (a common issue with e-learning packages) and miss out on any key parts of the lessons. As is common convention with e-learning packages, the button to go forward was placed on the bottom right hand corner. The button to go back to previous screens was located in the bottom left hand corner (again a common convention in e-learning packages). This can be seen circled in yellow in the screen shot example below taken from the Lesson 1 mock up (see figure 6).

Figure 6. Resource navigation

5.6.7 Controls

It was decided that learners should have a number of controls available to them as they worked through the lessons. These included volume control and voiceover on/off as well as ‘back’ and ‘continue’ buttons with clear icons. These conventions were observed in other e-learning packages and were felt to be appropriate for our audience. Learners would also have access to ‘skip’ buttons while viewing video and audio.
5.6.8 **Voiceovers**

In order to appeal to as many learning styles as possible it was decided to add voiceovers to the lessons. This gave learners the choice of reading sections of text or listening to them.

5.6.9 **PDF downloads**

In order to facilitate continued learning after the lessons were completed, we introduced the facility whereby learners would be able to download the work they completed in the course of the lessons, along with the lesson outline, scripts of scenarios and key learning points.

5.6.10 **Lesson elements**

When the case studies and scripts for the filming of the scenarios were complete, and the mock up versions of the lessons had been built, work focused on the development of the other lesson elements. Lessons were to contain key practice principles and practical strategies to deal with information sharing dilemmas. They would also contain questions, discussion points and team tasks to engage as wide a range of learning styles as possible. The lesson elements are shown in figure 7.

**Figure 7. Lesson elements within the resource**
The overall aim of each lesson is to illustrate a key information sharing principle or information sharing dilemma, in an engaging and informative manner. A number of different lesson elements are designed to achieve this. These are outlined below in more detail.

Firstly, the objectives of each lesson is clearly stated at the outset. This is recognised good practice in e-learning packages. These are designed to be clear and succinct. An example from lesson on is provided in figure 8.

Figure 8. An example of lesson objectives
Secondly, the learner is clearly introduced to the lesson structure. The lesson ‘menu’ page gives learners details of the steps contained in each lesson and how long it will take to complete (see figure 9 for an example).

**Figure 9. An example of lesson format**
Lesson context contains the summary scenario of each lesson to give learners a brief grounding in the type of scenario that would be contained within the lesson (see figure 10). It also informs the learner about the relationship between the carer and service user in the scenario.

**Figure 10. An example of lesson context**

The background information page provides the learner with more detailed information about the scenario and the situation of the characters. It is designed to give learners enough background information to understand the broader context when viewing the lessons for the first time and can be skipped if so desired on subsequent viewings.

A number of questions are posed throughout the lessons. The aim of this is to lead learners to think about the key points that the lesson illustrated and to reinforce these learning points. Learners are asked to answer questions in a variety of ways to appeal to different learning styles. In some cases they are simply asked to ‘click’ on the correct answer, whereas in others, they are asked to reflect and write their answers in scribble boxes. Learners are not allowed to move to the next stage without completing questions. If this is attempted a ‘pop up’ will come up preventing progress.

Discussion points are used in a similar manner to the questions (See figure 11 as an example). They are placed at intervals throughout the lessons to demonstrate key learning points. They help to reinforce learning and to generate discussion if the lessons are being worked through by more than one person at a time.
The video and audio clips show interactions between mental health professionals, carers and service users. They last between 30 seconds and 2 and half minutes before the learner is prompted with an action. Following on from questions and discussion points are a series of suggestions. These detail the reasons why some answers might be more appropriate than others and contained information on good practice and techniques to use to deal with information sharing dilemmas. The aim of these sections of the lessons is to detail practical strategies that learners can adopt when faced with real life information sharing dilemmas, such as those demonstrated in the video clips. They are designed to be grounded in real life practice and transferable to everyday practice situations. These parts of the lessons also contained links to further useful information (see figure 12 as an example).
After some of the lessons we include clips of the individual perspectives of all those involved. The aim of this is to encourage learners to see the scenario from a range of different perspectives and not just the familiar health professional perspective (see figure 13). Towards the end of each lesson there is a review of the objectives stated at the beginning of the lesson. This is recognised good practice in e-learning in helping to reinforce the overall aims of the learning.
Part of the interactive element of the course is to tie material in the resource to a learner’s current practice – their own case load. The reflexive sections are designed to encourage learners to reflect on the scenarios further and to relate what they had seen to their own work and current practice (see figure 14). Finally, the lessons suggest that learners take points from the resource to team meetings to promote discussions (see figure 15). These sections are again developed to bridge the gap between learning and practice. They are situated at the end of lessons and are designed to encourage learners to think about their own teams and actions that they could implement to improve practice.
Figure 14. An example of a reflexive task

Figure 15. An example of actions for you and your team
5.7 Discussion

5.7.1 Summary of key findings
Section 5 has focused on the steps involved in building the online learning resource. The build phase was technical and time intensive but it achieved its brief to create an online resource with two components: a website section to house information on confidentiality and information sharing with carers, and an interactive course to illustrate information sharing dilemmas and information sharing principles.

5.7.2 Limitations
The one limitation in the build phase was time. Although the project had been extended beyond the original project plan, the build phase was extremely demanding both in terms of developing the content and building the web site. The film company and technical web design team both overran on deadlines because of technical difficulties and problems that had not been foreseen which is common in projects of this kind.

5.7.3 Next steps
The online learning resource was designed and built to be accessible and useful to the target group of mental health professionals in negotiating information sharing dilemmas. The next step was to pilot the resource with mental health professionals and to undertake usability testing with the same group. These phases are outlined in the next section.
6 The piloting of the resource

This section describes the piloting of the resource. The pilot took place during August and September 2009 and the pilot online resource can be viewed at: http://rethink.minervation.net/. The revised resource is available at: www.carersandconfidentiality.co.uk

6.1 Objectives

The objectives of this phase were to:

- Pilot the interactive course component of the resource with a range of mental health professionals;
- Seek feedback on the information pages;
- Identify how to improve the resource through generating feedback from pilot participants;
- Seek advice over implementation across the NHS;
- Carry out a usability test.

6.2 Method

The pilot phase was conducted in four parts. Firstly, mental health professionals were recruited through NHS Trusts to complete and review the resource. Secondly, a sample of pilot participants were interviewed to capture in more detail their experience of using the resource. Thirdly, a range of stakeholders were asked for feedback, involving learning specialists, carers, policy leads, advice and information officers and carer support workers. Finally, Minervation carried out a usability test to assess acceptability and ease of use of the online resource with mental health professionals.

6.2.1 Pilot surveys and knowledge quiz

Mental health professionals from a range of professional backgrounds were recruited to use the interactive course component of the online learning resource, comment on the whole site and to complete pre and post online surveys to capture their experiences. Firstly, mental health professionals across the two development sites were recruited; mental health teams were asked to nominate participants from a variety of professional backgrounds to take part. Secondly, snowball recruitment was also used, utilising contacts within the steering group. Mental health professionals from thirteen NHS organisations registered to use the resource. Each participant was emailed instructions of how to take part in the pilot and web links to the surveys and resource materials to use (see appendices VI and VIII for copies of the instructions and surveys). The surveys were short in length.
and designed using the ‘survey monkey’ online survey programme. They were not designed to provide extensive data but to be brief and assist the development pathway for the resource. Participants followed an initial link to the pre course survey. They were automatically directed to the interactive course upon completion of the survey. When they had completed the course they were directed to the post course survey. The project team sent email invitations to 250 people. Participants who registered with the research team to complete the pilot were actively prompted by email at least twice with reminders to take part. The data from the survey was collated and analysed using SPSS.

6.2.2 Interviews with participants

A number of survey participants also completed a telephone interview with a project researcher. The interview used a semi-structured schedule (see appendix IX) with a sample of mental health professionals who indicated their willingness to be followed up. The interviews focused on ascertaining participants’ experiences of using the interactive course and to assess their views on the content and format. They also examined participants’ views on the impact of using the resource on their learning and practice. The interviews lasted 30 to 45 minutes with detailed notes recorded by the researcher. They were also audio-taped to allow the extraction of key quotations. These data were analysed thematically by two members of the project team.

6.2.3 Feedback from external experts

Feedback was gathered from other stakeholders, including carers and learning specialists, in two ways. Firstly, stakeholders who were not mental health professionals but had an interest in this area were asked to review the resource and complete a specific feedback survey. These contacts were recruited through our partner’s networks at Minervation. Secondly, stakeholders were asked to review the learning resource and email us with their comments. This includes feedback from members of the steering group. Participants were carers, mental health professionals, academics with an interest in the area, mental health advice and information officers in Rethink’s National Information and Advice Service (NIAS) and learning specialists. This information has been aggregated by reviewing all the comments received.

6.2.4 Usability testing

The usability testing phase of the project was conducted by Minervation in collaboration with the project team. We worked with six mental health professionals from our London development site. They worked with Minervation for a day following a standard usability testing process. We employed a pair-user method of testing the website. This method involves users working in pairs on tasks. It’s main benefit is in requiring users to make explicit decisions and thoughts which would otherwise remain implicit. This usually results in a greater quantity of feedback than with single user
sessions. It does, however, require careful facilitation and clear task-setting (Wilson, 1998; Wildman 1995). Tests were conducted using a MacBook Pro laptop with webcam and audio recording. User interactions were captured using Screenflow. This setup created a real-time video stream of the laptop screen with a video of test participants inset. Recordings have been provided as MOV files on an accompanying Data-DVD. The primary objectives of this phase of usability testing were:

- To measure the user acceptance of the applications user interface.
- To highlight areas of poor usability to be addressed prior to going live

The key questions explored during the tests were:

- Are users able to easily accomplish their tasks?
- Do users find the course elements engaging?
- Do users understand the different search and navigation elements, and are they able to use this to help them accomplish tasks?

During the usability phase ‘users’ are a term applied to people using the online resource.

### 6.3 Feedback from mental health professionals

#### 6.3.1 Participants

One hundred and fifty-five participants completed the pre course knowledge quiz and 65 participants completed the post course quiz plus feedback survey. Participants identified by the Trusts to take part were given unique identifiers to use when completing the surveys by a member of the project team. Participants recruited through snowballing techniques were sent instructions on how to generate their own identification codes. Missing identification data prevented a complete matching process thus quiz scores can be compared for only 51 participants.

Tables 9 and 10 below describe the pilot sample. The male to female ratio was approximately 2:3 across the three data sets. At pre-test (n=155) we had 29% male, 60% female and 11% undisclosed. At post test (n=65) there were 28% male, 66% female and 6 undisclosed participants. In the paired data there were 35 females (69%) and 16 males (31%).
Table 9. Professional background of pilot participants

<table>
<thead>
<tr>
<th>Professional background</th>
<th>Pre-test (n=155)</th>
<th>Post-test (n=65)</th>
<th>Paired data (n=51)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatry</td>
<td>17 (11%)</td>
<td>9 (14%)</td>
<td>7 (14%)</td>
</tr>
<tr>
<td>Nursing</td>
<td>69 (44%)</td>
<td>27 (41%)</td>
<td>23 (45%)</td>
</tr>
<tr>
<td>Social work</td>
<td>18 (12%)</td>
<td>5 (8%)</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Psychology</td>
<td>14 (9%)</td>
<td>11 (17%)</td>
<td>9 (17%)</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>9 (6%)</td>
<td>4 (6%)</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (6%)</td>
<td>2 (3%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>19 (12%)</td>
<td>7 (11%)</td>
<td>2 (4%)</td>
</tr>
</tbody>
</table>

Table 10. Settings in which survey participants worked

<table>
<thead>
<tr>
<th>Setting</th>
<th>Pre-test (n=155)</th>
<th>Post-test (n=65)</th>
<th>Paired data (n=51)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community mental health team</td>
<td>49 (31%)</td>
<td>22 (34%)</td>
<td>19 (37%)</td>
</tr>
<tr>
<td>Acute setting</td>
<td>42 (27%)</td>
<td>21 (32%)</td>
<td>17 (33%)</td>
</tr>
<tr>
<td>Early intervention services</td>
<td>13 (8%)</td>
<td>2 (3%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Rehabilitation unit</td>
<td>5 (4%)</td>
<td>2 (3%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Assertive outreach team</td>
<td>4 (3%)</td>
<td>2 (3%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Not known</td>
<td>29 (19%)</td>
<td>6 (9%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Other settings – e.g. home treatment teams, crisis teams, addictions, personality disorder, out-patients</td>
<td>13 (8%)</td>
<td>10 (16%)</td>
<td>9 (18%)</td>
</tr>
</tbody>
</table>

6.3.2 Survey feedback on the resource

Participants were asked to attempt three lessons and to review the information sections of the resource. Most (60%) did follow these instructions, and completed 3 lessons each in total across the nine available. Lesson 3 was the most commonly accessed module, lessons one, three and nine were also visited by a third of participants (see Table 11 and Figure 16 below). Unfortunately 26% of participants did not indicate which specific lessons they had viewed.
Table 11. Which lessons did you complete? (n=65)

<table>
<thead>
<tr>
<th>Lesson number</th>
<th>Theme</th>
<th>Number of participants</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Types of information</td>
<td>23</td>
<td>35%</td>
</tr>
<tr>
<td>2</td>
<td>Information sharing with fluctuating conditions</td>
<td>18</td>
<td>28%</td>
</tr>
<tr>
<td>3</td>
<td>Consent as process</td>
<td>29</td>
<td>45%</td>
</tr>
<tr>
<td>4</td>
<td>Possible risk to service user</td>
<td>16</td>
<td>25%</td>
</tr>
<tr>
<td>5</td>
<td>Uncertainty about levels of involvement</td>
<td>16</td>
<td>25%</td>
</tr>
<tr>
<td>6</td>
<td>Carer adjusting to changing circumstances</td>
<td>21</td>
<td>32%</td>
</tr>
<tr>
<td>7</td>
<td>Carer concerns about changing circumstances</td>
<td>5</td>
<td>8%</td>
</tr>
<tr>
<td>8</td>
<td>Discharge from hospital</td>
<td>7</td>
<td>11%</td>
</tr>
<tr>
<td>9</td>
<td>Carers sharing information with health professionals</td>
<td>23</td>
<td>35%</td>
</tr>
<tr>
<td>Not known</td>
<td></td>
<td>17</td>
<td>26%</td>
</tr>
</tbody>
</table>

Figure 16. How many lessons did the pilot participants complete? (n=48)
Additional feedback on the lessons was provided by ten participants. Five described difficulties they had experienced accessing the lessons because of Information Technology (IT) problems including slow download times for the films, and the other five reported positive experiences.

"Very informative and helpful - practical and applicable top modern practice. Used very 'everyday ' scenarios". (ID 27, Social worker)

"Videos stalled breaking flow of events. Otherwise really good“. (ID 26, Social worker)

Participant feedback on lesson content was broadly positive. The people who disagreed about the pitch of the content feedback felt that:

"The material was already familiar to me. I still hold that this is a great resource especially for newer members in the team and it might even be useful for teams to go through the lessons together to have a shared and common understanding and approach towards these complicated and on occasions contentious issues” (ID 22, Psychiatrist).

"Felt some of it too basic, took too long for me to go through the whole lesson compared to new information I learnt” (ID 59, Psychiatrist)

One person felt the material was not easy to understand, and felt that overall:  “Electronic learning does not work” (ID 67, Nurse)

This participant responded to all the questions in the same way – they did not like e-learning and felt it was an inappropriate medium for teaching.

Figure 17. Participant rating of lesson content (n=65)
Figure 17 summarises participant views on resource content. Most felt the content was easy to understand (95%), relevant to their work (98%) and pitched at the correct level (85%). Participants were also asked to comment on the content, 20 did. Again feedback was mostly positive (13 people), though 3 felt the content was too basic (two psychologists and a nurse who runs a carers group), two identified knowledge gaps they would like to see included and two people commented on IT issues.

“I am currently a manager - but as a social worker related to the application of this resource within current practice. Content easy, user friendly, articulate and thought / discussion provoking” (ID 1, Psychologist)

“I liked that the content was brief and to the point but relevant to current day practice” (ID 32, Nurse)

“The lessons do not mention the legislative context such as the Mental Capacity Act or carers legislation, which would be helpful. The scenarios I saw had carers who seemed to have the service user’s welfare at heart. It would be helpful to have scenarios where the service user alleges abuse by the carer.” (ID 31, Psychologist)

In relation to the psychologist’s points above, lesson 4 deals with a service user raising the issue of abuse by a carer. The links between the main website sections, where policy and legal frameworks are listed, and the interactive course are also going to be made more numerous when revisions are made following the pilot and usability phases.

The format of the resource was also reviewed by the participants (see Figure 18). Again feedback was broadly positive with most indecision prompted by asking whether the resource should be used for individual learning or within teams. This may reflect personal learning preferences as much as the suitability of the resource for use in team meetings.

“I think it would not work well as a whole team exercise, though perhaps a whole team discussion scheduled after a week in which every one did it”. (ID 17, Psychologist)

“With the technology we have available to us, it would be very difficult to undertake these lessons as a team. Also - people are less likely to put forward answers if they are unsure of them and conscious of other team members in a group setting - meaning that passive members of group training would probably learn very little”. (ID 61, OT)
The feedback also addressed participant views of the interactive features of the resource (see Figure 19). 97% agreed the course was sufficiently interactive, which was the main aim of this section of the resource. The voice-over feature was not viewed as useful by 35% of learners, 26% did not want to print out their work, and 28% did not find the audio and videos easy to access because of IT difficulties in some Trusts. This is a common theme within the feedback. We explored this in some detail with participating Trusts what IT problems were being encountered and why. Changes will be made to address these problems before the resource is disseminated.
The nine module lesson course was only part of the online learning resource. We did encourage participants to look at the other sections – 25% reviewed the information sections. Feedback was generally positive and included suggestions to improve the resource. People that did not look at the site indicated it was because they ran out of time.

“*Well set up and information sectioned appropriately. Subheadings allowed content to be easily read. Perhaps would be useful to have the information referred to in the modules e.g. module 1 further info on types of information, as pdfs or in a printable form so you have handouts*” (ID 19, Psychologist)

“*1) excellent, comprehensive, clear  2) clear, understandable  My one criticism - the link to all the policies is a bit daunting - it might be better to highlight the important parts and summarise the key issues somewhere*” (ID 44, Nurse)

“*Easy to find what you were looking for - I just tapped into specific parts of the website*” (ID 16, Psychologist)

The resource is designed as a learning tool to provide mental health professionals with knowledge and confidence to work more effectively with carers through information sharing. The feedback survey, thus, captured self-reported learning scores from participants (see Figure 20) to provide a basic indication of learning. A five point scale was used 1 indicating learnt a little, 5 learnt a lot. Everyone reportedly learnt something, and 63% rated 4 or 5 on the scale. The mean score was 3.48 (median 4).
The comments provided by participants confirmed that the resource was a useful ‘refresher’. It ‘consolidated’ existing learning, helped to make participants ‘feel more confident’ in the current practices, and made people ‘think about things’.

"It reinforced knowledge that I know but at times have forgotten it also was good to see the situations played out by others as I often find myself in similar dilemmas” (ID 47, Resource officer social services)

"I already knew a lot about sharing information with carers but still learnt stuff (ID 44, Nurse).

"Helped to me to clarify certain issues. The suggestions were very helpful. I liked the fact that it involved a variety of different teaching methods which appeal to different learning styles (ID 52, Nurse).

"The clarification of the three types of information was very helpful. The video raised issues and also ways of taking forward discussion with colleagues (ID 38, Social worker)

Learning was also assessed in the knowledge quiz. We received pre-test data from 155 participants, and post-test from 65. Matching pre and post scores by the unique ID given to each participant provided 51 'data pairs'. The results are summarised in Table 12.
Table 12. Knowledge quiz scores

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-test scores from 155 participants</td>
<td>2 to 10</td>
</tr>
<tr>
<td>Pre-test scores where we have data pairs (n=51)</td>
<td>2 to 8</td>
</tr>
<tr>
<td>Post test scores from 65 participants</td>
<td>5 to 9</td>
</tr>
<tr>
<td>Post test scores from data pairs (n=51)</td>
<td>5 to 8</td>
</tr>
<tr>
<td>Change score for data pairs</td>
<td>-2 to 5</td>
</tr>
</tbody>
</table>

We have not applied statistical tests to this data as the sample is small and selective. We observe that for each professional group the same directional change from lower to higher score pre to post test was found but can draw no conclusions.

Finally, participants were asked about linking the resource to their professional development portfolio. There was mixed views with only 24 people (37%) wanting to download a certificate of participation.

6.3.3 Interview feedback

From the survey, 20 professionals had volunteered to be interviewed, and we followed up 15 people. Participants were selected to provide a range of experiences – both in terms of their backgrounds and views expressed in the survey data. It was important to speak to those who had fed back critical comments as well as those that were broadly positive about the materials. Our sample came from different backgrounds including nursing (n=6), psychiatry (n=2), psychology (n=3), social work (n=2), nutrition and dietetics (n=1) and occupational therapy (n=1). They were drawn from 7 different organisations.

6.3.4 “Filling a gap”

There was a sense from participants’ responses that the learning resource was helping to draw attention to a subject on which there was currently little or no training available.

’Very relevant...I thought it was very applicable to current practice and dilemmas that practitioners face’ (ID 4, Social worker)

’I thought it was very clear, very helpful, very prompting....I thought it was of a very good standard...and very real...it didn’t feel phoney, or stupid, or a bit cheap....it felt like a very good, well thought through, articulate piece of work which gave examples that most clinicians would absolutely relate to – hurried conversations in a corridor, the pressure of disclosing the pressure
of not thinking through decisions about disclosing information…it seemed very helpful and it will be’ (ID 7, Ward nurse)

‘It highlights the things you know but just don’t do’ (ID 9, OT)

Participants also mentioned consistently that there was a real need for training of this kind.

‘It’s an area I have been interested in for a long time but there is very little guidance on working directly with carers in this way’ (ID 12, Psychologist)

### 6.3.5 Key aspects of the resource

Participants were asked to reflect on the resource and their experience in using different parts. All had used the interactive course with the video and audio clips. Participants gave positive feedback on the scenarios contained in the course.

‘I thought it was really spot on….I thought it was excellent, it was well constructed and the language of it was really good, I’ve been very impressed, and would certainly recommend it for use’ (ID 3, Social worker)

‘Overall this is a useful and relevant tool. The scenarios are real and are similar to those I face on an everyday basis. The main learning for me was that it has increased my awareness of the carer perspective. I intend to change my practice by revisiting issues more frequently. (ID 1, CPN)

Participants indicated that the scenarios were true to life and in keeping with day-to-day practice situations that occurred.

‘I could identify with the situations that I saw, and the examples that were used were very appropriate examples that reflected in situations that I have actually seen and echo aspects of my working life and the working lives of those around me’ (ID 5, Dietician)

Participants also commented that accessing visual content helped to bring the scenarios to life and to reinforce practical strategies.

‘It showed the potential dilemmas that you can find yourself in and showed the professional’s managing those with the carer and client as well’ (ID 8, Professional nurse lead).

A number of participants spoke about the effect of the lesson elements that punctuated the scenarios. In general participants commented that the questions and suggestions for practice helped to reinforce the learning points.
‘[questions were] thought-provoking... I consider myself as someone who likes to work with carers, I always take a very keen interest, I chair a regional carers group....so it did make me think – what happens when this happens?... Made me actually think, am I sure? What information can I share and what’s the law....it made me think about my own practice and I guess that’s what it should do’ (ID 4, Social worker)

‘The questions were clear, language aimed at professionals. I found them interesting and though-provoking’ (ID 11, Psychiatrist).

6.3.6 Impact on learning

The resource was produced as a learning resource. Feedback in the interviews emphasised that much of the information is not new, but the course is a useful revision exercise.

‘The feedback is useful and a good reminder for key points. The content dealt with everyday issues, it’s real and accurate no matter how much experience...it’s very good to be reminded, it’s a really good revision process as well’ (ID 2, Psychologist)

‘I felt the format with the aims/video/discussion/feedback – made the viewer think rather than just watching – therefore reinforcing the key learning points’ (ID 9, OT).

Several participants commented that having a pdf record of the work they had completed during the course of the lessons would be useful. A systematic assessment of the impact of the resource on individuals’ learning was outside the scope of this project. However, participants’ accounts suggest that the resource is useful for those who have used it. Importantly, a number of those interviewed (n=6) could identify things they would do to change their practice including revisiting consent more frequently and being more conscious of the carer perspective. It also helped one participant by reinforcing that her current practice was appropriate, providing renewed confidence in this area. A number of participants spoke about this in detail.

‘I intend to revisit cases more often and consider situations from a carer perspective more’ (ID 1, CPN)

‘It has made me rethink about issues around capacity and informed consent’ (ID 4, Social worker)

‘It has prompted me to put information sharing back on the agenda (team agenda, to be discussed in team meetings) I plan to use examples from the resource to see how the team think they would deal with them’ (ID 5, Dietician)
6.3.7 Raising awareness

The notion of having an increased awareness of issues around confidentiality and information sharing with carers was raised by a number of participants. When asked directly, ten felt that taking part in the pilot had increased their awareness of issues for carers, prompting them to consider the carer perspective a little more in future.

‘It certainly brought it to the forefront of my mind more so, ..and it was good to be made to think of it ahead of time rather than just in the moment when situations may arise’ (ID 2, Psychologist)

‘It has helped me to go back and look it again, and that’s been really really helpful....it’s made me think beyond my learning there are the practitioners that work in this team and there are daily issues of concern here, so it’ll enabled me to raise this with them’ (ID 3, Social worker)

6.3.8 Impact on knowledge

It appeared that using the resource also had an impact of participants’ knowledge of the subject. Six people emphasised that using the resource was a revision of knowledge, while another 6 felt it gave them something new.

‘I’ve become more aware of how to approach situations differently. Specifically I would revisit decisions more frequently with Service Users. If Service Users do not want to share info at all, I would do more now, as a result of the course, to outline benefits of allowing information to be shared. Previously I would have accepted Service User’s decision without trying to persuade them otherwise’ (ID 1, CPN)

‘I valued it as a reminder and refresher’ (ID 6, Nurse)

6.3.9 Confidence in dealing with information sharing dilemmas

The idea of having increased confidence in dealing with certain information dilemmas was present in the accounts of some participants. Ten people felt their confidence was addressed by taking part in the pilot, both reinforcing current practice as well as identifying new ways to work with carers.

‘I’m confident that I now have a resource to refer back to, it has made me forward plan and that increases my confidence to deal with these situations, it increased my confidence that the feedback provided on the questions was similar to the items I responded with’ (ID 2, Psychologist)
6.3.10 Suggestions for improvements

It was important to capture feedback on how to improve the resource. The first issue to address is IT, and dealing with the technical difficulties that some respondents experienced. In terms of content, some people wanted more information about carer organisations, there was a theme about links to legislation and policy in the lessons as well as the information sections of the resource and that the term ‘carer’ requires further attention. In addition for some learners there was insufficient context information provided around the scenarios to ‘make them more real’ e.g. information such as service user history and relationship between carer and service user.

‘If someone is detained under the Mental Health Act professionals have a responsibility to consult with the nearest relative, and gathering information from other relevant people as part of the Mental Health Act assessment – this is different from any other situation – this was not made clear’ (ID6, Nurse)

‘Use some bad practice examples to illustrate what not to do’ (ID 8, Professional nurse lead)

A couple of participants felt the actors, although realistic should have been more diverse. Budget constraints meant we had to use the same actors in different scenes, which some learners found unhelpful.

6.3.11 Implementation of resource

There was much discussion with participants about the factors that should be in place to facilitate the use of the resource. Participants did emphasise that for the resource to be used more widely, beyond the pilot it would need Trust management endorsement and recommendation, alongside a link to the NHS KSF (Knowledge Skills Framework) including CPD (Continuing Professional Development). One suggestion was that it could be part of mandatory training within the Trust induction programme, which in their Trust already had a number of e-learning elements including a system where on wards staff were given laptop computers to specifically complete mandatory modules. Another participant felt strongly it should not be part of mandatory training as that would stop staff engaging with it – they recommended it was used by managers who then encouraged their teams to use the resource, followed up by supervision and team discussion.

‘Support is necessary, the course would have to be seen as something necessary and staff provided with the time to do the training. It would have to be supported by the senior management’ (ID 1, Social worker)

‘The Trust would have to advertise the resource, demonstrations or incorporate it into a team brief to spur interest in it. If people saw it they would see the value in doing it more so’ (ID 3, Social worker)

"I think it’s going to be a useful resource and I hope it does get rolled out and used’ (ID7, Ward nurse)
6.4 Feedback from other stakeholders

We received detailed feedback from four carers, a carer support manager and a policy lead in another voluntary sector organisation that supports carers. In addition the Minervation network of contacts enabled us to share the resource with ten learning experts. One could not access the interactive course which she found disappointing: "Unable to complete course as the video kept stopping every few seconds - really frustrating. Would really like to complete the course but unable to when the video not working properly". Feedback from the other learning specialists was positive:

"I thought the content was excellent and I really liked the layout. I looked at one PDF document on 'Dealing with unusual thoughts and behaviours' and found it easy to understand. I think that type of document is particularly useful for carers but could be improved by a better graphical display, using images and photos. I would suggest the reading ability would need to be pretty high so might be suitable for everyone". (Librarian, NHS Information)

"Suitable for both individual and group use - perhaps greater honesty from individual use particularly if states that notes are for private use only when the scribble pad appears as that is not clear at present". (Patient information, NHS Trust)

"Content is very informative without being stuffy and leads very logically into the detail. The layout is very clear and attractively simple". (External corporate consultant, Private company)

"Still a bit too much jargon? Why not write about working together rather than collaboration for example? This is more an observation of the general text than the interactive element" (General health consultant)

Feedback from our carer experts was positive although they provided several suggestions for changes. In particular:

- Making it more obvious at the start why working with carers is beneficial, why cooperation leads to better outcomes and consistency of care;
- Definition of carers – need to qualify ‘paid carers’ who can also be called care workers;
- Update section on National Carers Strategy and link to professional organisation for more details;
- Summarise key legislation before linking to detailed documents
- Types of information section:

  "There needs to be a little more emphasis on the point that carers can be given general information about mental illness, the Mental Health Act, and services to support them as carers regardless of service user consent“ (Policy Lead)
• Need to add Lasting Power of Attorney to good practice strategies section;
• Recommended additions to add to scenario 'suggestions' section – such as in lesson one:

"Point of clarification: Ravi does not have the right to prevent the doctor from seeing his mother separately. The doctor’s response to Ravi’s unease seems to suggest that Ravi can forbid the doctor from engaging with his mother. This is not the case, as Ravi has no legal right to do so. However, the doctor can indeed make a professional judgement to this effect. It would be helpful to have this clarified in the final suggestions". (Policy lead)

"This looks really good. I especially liked the interactive bit, and thought the acting was excellent. Just wondered whether you need to explain that the same actor will be playing different roles" (Carer support worker)

"I really like the way where you portrayed positive and negative outcomes with carers which were dependent upon the way in which the staff member tackled the issue within some of the case studies. It brought back a lot of memories of how badly they dealt with me. My main comment is that I feel that it would be even better if you could get the psychiatrist in the first video exercise to discuss in detail the three types of information. I know that there are links within the exercise to further detail regarding the three types of information (although they weren’t working yet) but I feel that this issue is so fundamental that it would be better if the psychiatrist discussed the difference between them at this early stage in the training" (Carer)

"Thanks for the link, I have had a good look through the programme and think it is a very important resource tool. I enjoyed going through the different sections and was disappointed not to be able to save them as a pdf as a personal development tool. I look forward to when it goes online". (Carer)
6.5 Usability testing

The final phase of the pilot was a standard usability test with mental health professionals – the resource ‘users’. We worked with 6 mental health professionals: 4 CPNs, one OT and one deputy team manager who had previously been a CPN. It carrying out usability testing the competence of the group in using web sites is relevant. On a scale of 1 to 10, one participant rated their familiarity with the internet as 3, one rated 5, two rated 6 and two rated 7. In terms of time spent on-line 3 spend 1 to 5 hours per week on the internet, 2 rated their use as 5-10 hours and one person over 10 hours. Appendix X provides more detail on both the participants and the usability testing process. The findings from the test are provided in Tables 13 to 15.

Table 13. Are users able to easily accomplish their tasks?

<table>
<thead>
<tr>
<th>Questions:</th>
<th>Positive comments</th>
<th>Negative comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Can users quickly orientate themselves on the website?</td>
<td>a. Users felt that the homepage design was fit for purpose, i.e. plain and professional, as befits a site aimed at mental health staff.</td>
<td>a. Initial feedback on the homepage design was reserved. Users felt that it was somewhat bland and not immediately appealing.</td>
</tr>
<tr>
<td>• Do they understand what the site is about and who it is for?</td>
<td>b. Users read the introductory text and on the whole grasped the purpose of the site.</td>
<td>b. The majority of users did not like the image used on the homepage of the actor from the video clip. It was felt, following some discussion, that this may work as a video clip that plays when the homepage is loaded.</td>
</tr>
<tr>
<td>• Are users comfortable with the layout and design?</td>
<td>c. Some users felt that the homepage welcome text and bullet points could be improved, i.e. made clearer and more succinct.</td>
<td>c. Some users were unsure about what they might find in the interactive course.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Implement homepage video clip</td>
<td>a. To do</td>
</tr>
<tr>
<td>b. Rephrase welcome text and homepage bullet points. Have four bullet points; one for each category in the menu (working with carers, information sharing principles, good practice strategies, interactive course).</td>
<td>b. Completed</td>
</tr>
</tbody>
</table>
Table 14. Do users find the course elements engaging?

**Questions:**
- How do users respond to the initial concept of an interactive course? Do they feel it is worth registering?
- Do they find the course layout and design appealing?
- How do they respond to the various multimedia elements?

<table>
<thead>
<tr>
<th>Positive comments</th>
<th>Negative comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Once users understood the benefits of registration, all were keen to register and participate in the course.</td>
<td>a. All users were put off by having to register and felt that this was required because Rethink wanted to capture information about them and track their use of the site, rather than for any benefits they might gain themselves.</td>
</tr>
<tr>
<td>b. Opinions were mixed about the design of the interactive course pages (notably the black background), but after using it most users felt that the design worked well. It was noted that the colour scheme helped those with visual impairment.</td>
<td>b. All users struggled to register on the site because of the layout of the registration page.</td>
</tr>
<tr>
<td>c. Users responded well to the course scenarios and video content. They felt that the situations were believable and the acting vivid and thought-provoking.</td>
<td>c. Some users expressed concern about the voice-over. It was generally felt that this worked well when used sparingly, but not on long pages of text.</td>
</tr>
<tr>
<td>d. Users thought that the course worked well when it was viewed in pairs, because this encouraged debate.</td>
<td>d. Users felt that the course content was pitched at quite a low level and that the tone of some content (e.g. the phrase ‘scribble box’) was rather patronising.</td>
</tr>
<tr>
<td>e. Users felt that the course content and style compared very favourably to other eLearning they had experienced.</td>
<td>e. Users struggled to answer the questions in the quiz. It was felt that the quiz format was unnecessarily complicated and did not motivate people to learn.</td>
</tr>
</tbody>
</table>

**Recommendations**

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Make the benefits of registration clear on the main interactive course page, e.g. by registering you will be able to save your progress through the course, print off your work and obtain your course certificate on completion.</td>
<td>a. To do</td>
</tr>
<tr>
<td>b. Ensure that the registration page is easily accessible from the interactive course page.</td>
<td>b. To do</td>
</tr>
<tr>
<td>c. Improve the usability of the registration form</td>
<td>c. To do</td>
</tr>
<tr>
<td>d. Ensure all course content has a professional/formal and non-patronising tone.</td>
<td>d. To do – changing scribble pad term</td>
</tr>
<tr>
<td>e. Ensure that the time estimates given at the beginning of the course are accurate.</td>
<td>e. To do</td>
</tr>
<tr>
<td>f. Simplify the quiz format and content. Make the questions easier and provide one link for each question that is answered incorrectly.</td>
<td>f. To do</td>
</tr>
<tr>
<td>g. Increase the time out on the login so users who take a long time to complete a lesson do not lose their work.</td>
<td>g. To do</td>
</tr>
</tbody>
</table>
Table 15.  Do users understand the different search and navigation elements?

<table>
<thead>
<tr>
<th>Questions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Is the main menu of the website clear and usable?</td>
</tr>
<tr>
<td>• Can users browse and find answers to their questions about information sharing?</td>
</tr>
<tr>
<td>• Can users move through the course effectively, using the various navigational elements?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Positive comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Users responded well to the simple website structure and felt that it facilitated their use of the site.</td>
</tr>
<tr>
<td>b. The majority of users quickly understood the interactive course homepage.</td>
</tr>
<tr>
<td>c. Users found the course controls (e.g. lesson page numbering, mute/volume) quite intuitive.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Negative comments</th>
</tr>
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<tbody>
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<td></td>
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<table>
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<tr>
<th>Recommendations</th>
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6.6 Discussion

6.6.1 Summary of key findings

The pilot has revealed a significant challenge with implementing e-learning resources because of NHS computer system difficulties. We invited 250 professionals to take part, 155 were motivated to register but only 65 provided feedback after using the interactive course. Some participants reported extensive delays with downloading the video lessons. Discussions with Trusts at the build stage indicated that connection speeds were at least 1MB. Thus, the interactive resource was optimised to perform best at this speed. It appears that was not the case. The challenge will be addressed when the resource is implemented more widely with separate download speed options: 512kb for dial up connections, 1MB for medium speed connections and 2MB for standard broadband connections.

The second challenge revealed by the pilot is the training medium of e-learning. In section three we learnt that Trusts preferred style for learning about carer issues was face to face training with ‘real’ carers (see section 3.4, table 4). In the pilot we achieved a very poor response rate with only 26% of invited practitioners providing post-completion feedback to indicate they had used the resource. This could indicate a resistance with using e-learning to engage with issues relating to mental health carers specifically and learning more generally. However, as the learning platforms across the NHS embed more e-learning modules in professional development programmes, familiarity and confidence with this medium should follow. It
is likely there will be staff whose preferred medium of learning will never be visual through on-line or CD rom and this will need to be taken into account when designing Trust wide carer awareness programmes for staff.

Where staff had used the resource feedback was broadly positive. This crossed all professional groups, and there was a mix of participants including 44% from nursing, 12% social work and 11% psychiatry. Overall, participants felt it was practical, helpful, realistic and useful. All participants reportedly ‘learnt a little’ and 63% ‘learnt a great deal’. This learning was gaining new knowledge, revisiting information they had been trained in previously or read about in guidance and policy documents, gaining greater awareness of the carer perspective or refreshing this viewpoint as well as improving confidence to share information based on a best practice framework. Most (97%) felt the resource was sufficiently interactive although one participant was extremely negative stating ‘e-learning does not work’. The usability testing also indicated the tool was broadly accessible and useful.

Feedback did raise a concern over the ‘pitch’ of the resource although 55 participants (85%) agreed the content was the correct level for their role. A few participants felt the material was too basic, but useful to junior staff. This was picked up in the usability testing as well. The resource was designed to appeal to different practitioners’ preferred ways of learning, with options to override several features. Feedback suggests that this was achieved, with 37% requesting a downloadable record of their learning but others not findings this option useful. Many liked the voiceovers, others (11%) did not and 24% were undecided.

The participants have highlighted a number of changes to improve the resource. These include a glossary of terms and a summary of some of the key legislation ensuring that more layers of information are available. There needs to be more links between the interactive course material and the information sections of the web site. A case where the carer is exploitative and abusive to the service user needs greater prominence. The usability testing has highlighted some technical changes to improve access. These include amending the registration process, changing the ‘timed out’ feature, adding a video clip to the front page. Most changes to content have been implemented. These are documented in detail in appendix XI. The technical changes will be made by Minervation before the resource is launched.

Recommendations for implementation suggest that the approach could either be through teams, with individual learning supported by team discussion, or within a mandatory induction course.

6.6.2 Limitations

The pilot is limited by the sample size. The target was to recruit 160 mental health professionals from diverse backgrounds, which was nearly achieved with 155 submitting the post-test survey. However, follow-up data is only available for 65 people. This is likely to have been caused by:
• The pilot taking place over the summer vacation – August and September;
• There were problems with identifier numbers, particularly where individuals were reliant on generating their own, limiting our ability to match pre- and post-test scores;
• Technical difficulties within some Trusts in accessing the interactive course. All of our preliminary discussions with Trusts indicated that connection speeds were at least 1MB. Therefore, the interactive resource was optimised to perform best at this speed. However, when there is pressure on the system, for example early morning when staff log onto email accounts, connection speeds are reduced. This will be addressed when the resource is revised;
• The course did not interest participants sufficiently to complete the modules and provide feedback. This has implications for implementation. If the pilot only engaged the motivated few, we will have to take active steps to ensure those less interested in carers and motivated to learn use the resource.

The pilot was designed to assess participant views on the format and content of the resource, and experiences of using the interactive lessons in particular. It did not ask participants to rate their confidence prior to using the tool and on completion which was an oversight. It would have been useful to assess self-rated views of confidence as this emerged from the qualitative data as one of the outcomes of using the tool.

The pilot also did not assess the impact of the resource on clinical practice including outcomes for both mental health services users and carers. This was never the intention of the development phase but would be a useful next step.

6.6.3 Next steps

The feedback generated in the pilot has been used to revise the online tool. A number of changes have been made (as documented in appendix XI) and a few more will be required prior to its launch. These relate to technical aspects and will not affect the formatting or content.
7 Discussion

7.1 Summary

Through four main phases of the project, we have developed an online learning resource for mental health professionals working in England and Wales. The consultation phases confirmed that training on information sharing with carers was required and that such a resource would complement other packages addressing the role and needs of carers.

The consultation phase also stressed that the resource would need to be practical and engaging. This was addressed by producing an interactive video and audio based nine lesson course, and information sections on three main web pages to cover: working with carers; information sharing principles; and good practice strategies. The pilot version can be found at: http://rethink.minervation.net/ Feedback from pilot participants revealed the resource was sufficiently interactive and practical. The pilot phase demonstrated that for practitioners who worked through the resource, the majority found it beneficial and they have started to identify ways in which to put the resource into practice. This was the case for practitioners across several professions including psychiatry, social work, nursing occupational therapy, psychology, and those in management positions.

A solution is required before wide implementation to overcome the IT problems that beset participants in the pilot. Too many people struggled with the videos uploading within the interactive course. This must be overcome to ensure that learners have easy access to the resource and can use it efficiently. Another barrier will be the registration process. Learners will need to register their details to use the resource, in order that their learning can be tracked and a certificate of completion issued for the professional development portfolio. The usability testing showed this was a barrier and people were suspicious of the need to register. Changes have already been made to the site based upon feedback from the pilot and usability phases (see appendix XI for a summary). The revised resource can be viewed at: www.carersandconfidentiality.org.uk

The consultation phase revealed that implementation would be a challenge, as mental health professionals have limited time to undertake training. An e-learning format was developed to address some of these difficulties, as it introduces more flexibility to learning, but it is not a format that everyone engages with easily. On the topic of information sharing with carers, face to face training which included carer trainers was preferred by most NHS Trusts who replied to our survey. The current resource was developed to complement existing activities, not to replace existing training on carer related issues. The e-learning package is designed as a starting point, to be followed up in team discussions and other workshops, as well as providing sufficient information to stand alone.
as a learning module. In the pilot we may have reached the staff who are particularly motivated and interested in e-learning and carers. The implementation strategy will consider how to reach all learners across mental health NHS Trusts, taking into account the recommendations provided in the pilot. In particular, the importance of senior management support and team leader champions to recommend and encourage use of the resource and accompanying handouts will be explored.

7.2 Limitations

There are a number of project limitations. Firstly, the project has evolved and the delivered resource is different from the training proposed in the original submission. This is a project strength, as plans were modified in response to feedback from learners and organisations. It has, however, meant that the project took longer to complete than anticipated and it was not as well-planned as it might have been had an e-learning programme been planned from the outset.

The resource was developed in a number of stages. The final two stages, piloting and usability testing were hurried. The project did encounter a number of delays caused by staffing issues, delayed funding decisions and technical difficulties. Both the editing of the short films to create the nine-lesson interactive course and the building of the website took longer than planned. This meant the pilot was both shorter than planned and was carried out when many staff take annual leave over the summer period. We did not pilot the resource with as many practitioners as anticipated. There is a possibility that those who used the resource during the pilot and usability stages represent those with a prior interest in the topic. The implementation stage will have to reach a wider group, who may be less motivated to learn and engage with the carers and confidentiality topic.

Finally, as explained in earlier sections the project was a practice development initiative and not a piece of scientific research. However it has used research methods as the basis for the development process. The overall collation of findings and consultation that firstly lead to the decision to build an e-learning resource and secondly to build the content and framework for the resource provided evidence for the team on the needs of staff and the key areas to address through the resource. This evidence was not consistent in favour of e-learning, and it is possible that we engaged with practitioner enthusiasts and have produced as much a technical as a needs based solution. However the culture of learning in the NHS is moving towards technology platforms and this medium presents value for money. Finally, and critically, the sites chosen for the development and pilot were purposefully sampled, different consultation methods had to be pragmatically employed in different sites, low response rates to the practice survey in chapter 3 and recruitment and poor response in piloting in chapter 6 introduce probable bias. This does not detract from the thorough development of the resource but it is important to take this into account when assessing the development pathway.
7.3 Implementation plan

The project was always concerned with how to implement the training resource once developed. Consultation and piloting confirmed that the learning environment within NHS Trusts is challenged by staff time and resource restrictions. The project team have identified a number of ‘next steps’ for the resource prior to implementation to improve uptake of the training. These are detailed below:

- The resource will be amended in line with recommendations from the pilot and usability testing to improve the tool. Most of these changes have been completed;
- There are currently 60 Mental Health NHS Trusts. The CEO, medical director and director of nursing in each will be contacted by letter to introduce the resource and request that a lead champion is identified if they would like to implement it locally;
- Identified champions will be contacted to discuss a plan for implementing locally. For example, a Trust may just use it on acute wards in first instance or alternatively only within CMHTs. It will also involve discussing IT requirements. We can place the videos in three different speed formats: for extremely slow internet connections, medium speed connections and fast connections. Only Trusts that identify a lead will be able to use the resource in the first phase of implementation;
- E-publicity material for the resource will be prepared and distributed in Trusts signed up to use the resource;
- Trusts will be encouraged to supplement these materials and make use of their own networks to promote the use of the resource e.g. on the internal intranet and other communication platforms that staff access.
- Trusts that do not respond will be contacted directly by telephone to explore whether they would like to use the resource or reasons for not using;
- A brief carer toolkit will be developed to assist carer campaigners to promote the use of the learning resource in their locality;
- The implementation phase will also look at options for participating Trusts to pay a small licence charge for use to cover upgrade expenses. No decision on charging has been taken at this time. The project team need to balance the priority that this tool is used, to benefit carers and service users, against the practical constraint that it will need maintaining and funds to cover these on-going costs.

The implementation timescale is in two stages. Firstly, amendments to the resource will be made while the final report (this document) is under review by the funder by both Minervation and Rethink. Secondly, the dissemination of the final resource by Rethink (www.carersandconfidentiality.co.uk) will take place from May 2010. It will be a phased dissemination involving a
collection of Trusts at each stage so that feedback can be incorporated. The aim is to make the resource available to all NHS Trusts across England by March 2011. We anticipate six stages of promotion and dissemination support. We do not expect each NHS Trust to use the resource in the same way. Our aim is get each Trust to trial the use of the tool with a view to embedding more widely based upon appropriate feedback. Some Trusts will choose in-patient wards as the first teams to use the resource, others will select community based teams. We will also be piloting a charging system as the maintenance of the resource must be covered. This will be crucial in developing partnerships with the Trusts as the implementation phase of the project can not succeed without successful collaborations with the end user organisations.

7.4 **Further research and development**

There are several recommendations for further work using the resource. These are listed below:

- An independent research study to assess the impact of using the tool on the confidence of mental health professionals in dealing with information sharing dilemmas and their clinical practice, and measure the impact on carers. We suggest a team could use the resource within an RCT or cluster RCT study design. Comparative studies assessing our e-learning resource with other training mediums or packages with carers among other patient groups could also be developed.

- An economic evaluation of the impact of using the resource (either in isolation or in combination with other training resources) addressing outcomes for carers, service users and the value to Trusts in terms of a reduction in the number of related complaints.

- The project team need to consider other formats for the resource e.g. placing video clips on DVD for mental health professionals with very slow internet connections as an alternative to the online package to aid implementation.

- Seek endorsement of the resource from professional bodies such as the Royal College of Psychiatrists, Royal College of Nursing as well as bodies such as Sector Skills Council.

- Explore how the tool could be used in pre-registration training of key professional groups – psychiatrists, social workers, nurses, occupational therapists and psychologists.

- Explore how the resource could be integrated with other NHS e-learning initiatives e.g. national learning management system. It is currently on a site hosted by Minervation but this could change and the resource could become embedded within the Trusts own e-learning platform.

- Explore the suitability of use of the tool with social services and voluntary sector staff.
• Explore how the resource can be used within a ‘jigsaw’ of learning initiatives and practical programmes to support carers. It should not be viewed as a stand alone piece of work

• Explore whether the resource would be useful for other learners outside of NHS environments, such as staff working in the voluntary sector and social services.
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Appendix I: History of the information sharing resource project

<table>
<thead>
<tr>
<th>Phase</th>
<th>Timescale and explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>First SDO funded study on information sharing with carers commissioned.</td>
<td>Study commenced August 2003.</td>
</tr>
<tr>
<td>Submission of first report</td>
<td>June 2004</td>
</tr>
<tr>
<td>Submission of revised report following reviewer feedback</td>
<td>Positive and inclusive? Effective ways for professionals to involve carers in information sharing. November 2004</td>
</tr>
<tr>
<td>Full report available to download from SDO website</td>
<td>2005</td>
</tr>
<tr>
<td>Briefing paper drafted</td>
<td>2005</td>
</tr>
<tr>
<td>Discussion with SDO about training resource</td>
<td>Proposal submitted summer 2006 and the feedback was SDO were interested in a piece of work with a far smaller budget.</td>
</tr>
<tr>
<td>Submission of full application to SDO for training resource</td>
<td>November 2006 submitted scaled down proposal to develop a training resource by working in fewer pilot sites.</td>
</tr>
<tr>
<td>Study commissioned</td>
<td>Start date in contract set as April 2007. We delayed commencement until staff member was in post – June 2007. This was approved by SDO.</td>
</tr>
<tr>
<td>Study set up meeting</td>
<td>July 2007 – project meeting with SDO. We discussed ideas for resource and possibility of on-line learning materials. SDO requested a new proposal to cover cost of on-line development.</td>
</tr>
<tr>
<td>Staff member resigned</td>
<td>We unfortunately lost our new member of staff in October 2007.</td>
</tr>
<tr>
<td>Project suspension requested</td>
<td>We requested a no-cost project suspension for 3 months from October 2007 to January 2008.</td>
</tr>
<tr>
<td>New project manager appointed</td>
<td>We had previously appointed a carer expert to run the study. This was important as the resource was to be carer-led training. However, as the resource specification potentially changed to on-line learning we altered the role and employed an experienced researcher to the study with practice development skills. They came into post February 2008.</td>
</tr>
<tr>
<td>Submission of new proposal to SDO for additional funds for on-line resource</td>
<td>January 2008. This was submitted by Rethink, University of Swansea and Minervation</td>
</tr>
<tr>
<td>Decision from SDO to provide additional funds</td>
<td>August 2008.</td>
</tr>
<tr>
<td>Exit meeting with SDO based at LSHTM</td>
<td>February 2009 where a project extension until 31st September 2009 was agreed.</td>
</tr>
</tbody>
</table>
Appendix II: Extracts of original data

The full data set and analysis can be found at:
http://www.sdo.nihr.ac.uk/files/project/54-final-report.pdf

1. Service user concerns over information sharing

Most of the service user sample (n=168) were broadly supportive of carer empowerment, carers being involved in their care and are willing for personal information to be shared as long as service user consent is provided. However, 1 in 3 service users in the sample are not comfortable with information being shared without their consent or for carers to have separate time with professionals. The main identified concerns are summarised in Table 1 and the selected text extracts below.

Table 1: Service user views of main professional-carer information sharing problems

<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of responses (n=101)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General Issues: Information sharing practice problems</strong></td>
<td>45 (45%)</td>
</tr>
<tr>
<td>Information should not be shared without service user consent</td>
<td>11</td>
</tr>
<tr>
<td>Misinterpretation of information among professionals and carers</td>
<td>7</td>
</tr>
<tr>
<td>Problems relating to professional role</td>
<td>46 (46%)</td>
</tr>
<tr>
<td>Incorrect information shared, professional opinion may change</td>
<td>9</td>
</tr>
<tr>
<td><strong>Lack of understanding limits confidentiality, confidences broken</strong></td>
<td>8</td>
</tr>
<tr>
<td>Damaging relationship between professional and user</td>
<td>5</td>
</tr>
<tr>
<td>Professionals do not attempt to engage with carers, thus don’t share info</td>
<td>5</td>
</tr>
<tr>
<td>Problems relating to the carer role e.g. information shared will cause carers to worry, carers feel unable to ask for information,</td>
<td>15 (15%)</td>
</tr>
<tr>
<td>Problems for service user</td>
<td>22 (22%)</td>
</tr>
<tr>
<td>Service user disempowered: user voice silenced, ignored, undermining independence</td>
<td>10</td>
</tr>
</tbody>
</table>

(In the original report this is Table 11)

Service users recognize that professionals are not adept at knowing what information can and should be shared with carers, alongside specific concerns over the appropriateness of information sharing with the carer. Service user suggested solutions include promoting better 3-way communication, the use of advance directives and principles governing the use of meetings to share information (see Table 2).
“Service user’s voice may be silenced by professionals and carers believing that they always know best. (That is why tripartite meetings are best). Also, depends on the quality of the professional and carer - very difficult to generalise” (SU30)

“It can become like a game of Chinese Whispers. I object to information sharing without my being told what information is being shared so that I can correct errors. I think that it can also cause rifts in families” (SU67)

Table 2: Suggested solutions to overcome barriers to information sharing in mental health - service user perspectives

<table>
<thead>
<tr>
<th>Service user solutions:</th>
<th>Number of service users (n=62)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better communication, openness and honesty between professionals, carers and service users</td>
<td>25</td>
</tr>
<tr>
<td>Written agreement outlining what can (and cannot) be shared with carers e.g. advance statement</td>
<td>18</td>
</tr>
<tr>
<td>Respecting other people’s perspectives, addressing these differences in building relationships</td>
<td>4</td>
</tr>
<tr>
<td>Providing copies of written reports and letter to service users, and when consent is given to carers</td>
<td>4</td>
</tr>
<tr>
<td>Meetings: user always present when information is shared</td>
<td>4</td>
</tr>
<tr>
<td>Meetings: meeting held individually (with carer or service user) and jointly (3-way)</td>
<td>1</td>
</tr>
<tr>
<td>Meetings: Acknowledge that carers work, can’t always attend meetings – need alternative ways to share information (flexibility)</td>
<td>1</td>
</tr>
<tr>
<td>Education: Provide more resources for carers (leaflets, training courses)</td>
<td>2</td>
</tr>
<tr>
<td>Education: Provide better training for professionals on working with carers</td>
<td>2</td>
</tr>
<tr>
<td>Create time to share information</td>
<td>2</td>
</tr>
<tr>
<td>Listen carefully to service users so that inaccurate information is not shared</td>
<td>2</td>
</tr>
<tr>
<td>Use the NHS complaints procedure to address problems</td>
<td>2</td>
</tr>
<tr>
<td>Use e-mail to speed up transfer of information</td>
<td>1</td>
</tr>
<tr>
<td>Use jargon free language when information sharing with carers and service users</td>
<td>1</td>
</tr>
<tr>
<td>Support service user to understand issues around consent</td>
<td>1</td>
</tr>
<tr>
<td>Build better therapeutic relationships – basis for trust to aid sharing of information</td>
<td>1</td>
</tr>
<tr>
<td>Pro-active users challenging (encouraging) professionals to involve the carer</td>
<td>1</td>
</tr>
<tr>
<td>Use of advocates instead of carers</td>
<td>1</td>
</tr>
<tr>
<td>Avoid using mental health services</td>
<td>1</td>
</tr>
<tr>
<td>Reciprocal rights respected – user can expect to know as much about carer as carer knows about user</td>
<td>1</td>
</tr>
<tr>
<td>Incorporate information sharing within CPA process more effectively</td>
<td>1</td>
</tr>
<tr>
<td>Psychiatrists sharing decision making (and their power) with care team, users and carers</td>
<td>1</td>
</tr>
</tbody>
</table>

(In the original report this is Table 12)
2. Carer concerns over information sharing

The new resource will directly address the training needs of mental health staff. The goal is to also attend to the concerns of carers that staff often do not share information with them in a timely or appropriate way. The original research collected data on the views of 496 carers. 1 in 3 carers reported they did not have sufficient information to support them and only 56% of carers report having the opportunity to discuss information they have come across with mental health professionals. The consequences of poor information sharing for SMI carers are provided in Table 3.

Table 3: Consequences of poor information sharing with carers

<table>
<thead>
<tr>
<th>SMI carer response:</th>
<th>Number of respondents (n=252)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers lack of knowledge and information to support them in their caring role</td>
<td>78 31%</td>
<td></td>
</tr>
<tr>
<td>Carers not being involved and listened to in areas where their involvement could make a difference in terms of outcomes for the service user</td>
<td>40 16%</td>
<td></td>
</tr>
<tr>
<td>Mental health of service user affected through delayed access to help or loss of social support e.g. accommodation</td>
<td>36 14%</td>
<td></td>
</tr>
<tr>
<td>Carer lacks skills to effectively support service user</td>
<td>35 14%</td>
<td></td>
</tr>
<tr>
<td>Service user is discharged from hospital without carer knowledge and support</td>
<td>30 12%</td>
<td></td>
</tr>
<tr>
<td>Health of carer affected – through worry, anxiety</td>
<td>18 7%</td>
<td></td>
</tr>
<tr>
<td>Opportunities for professionals to learn important in formation about service user and context of illness lost – carers a rich source of information</td>
<td>17 7%</td>
<td></td>
</tr>
</tbody>
</table>

(In the original report this is Table 16)

Helping staff to understand the consequences of poor information sharing could be one goal of the new resource. This will be explored in the development phase. Do mental health professionals feel they pay sufficient attention to appropriate information sharing with carers, and understand the consequences of poor information sharing?

Carers from the original NIHR SDO study also suggested possible solutions. A summary is provided in Table 4 from SMI carers.
Table 4: Carers views on how poor information sharing practices can be avoided

<table>
<thead>
<tr>
<th>SMI carer response:</th>
<th>Number of respondents (n=254)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve communication within the mental health system between all parties –</td>
<td></td>
<td></td>
</tr>
<tr>
<td>professionals, service users and carers</td>
<td>49</td>
<td>19%</td>
</tr>
<tr>
<td>Professionals must recognise the expertise and experience of carers. By changing attitudes towards carers problems can be overcome.</td>
<td>48</td>
<td>19%</td>
</tr>
<tr>
<td>Change professional culture to embrace partnership working with carers. A cultural shift is required to involve SMI carers in mental health care</td>
<td>41</td>
<td>16%</td>
</tr>
<tr>
<td>By providing carers with specific supports and services including carers assessment, respite, support workers, support groups, information resource packs, carer education programmes</td>
<td>41</td>
<td>16%</td>
</tr>
<tr>
<td>Improve the quality of mental health services delivered to service users living with SMI</td>
<td>38</td>
<td>15%</td>
</tr>
<tr>
<td>Involve carers in meetings, discussions, written correspondence</td>
<td>32</td>
<td>13%</td>
</tr>
<tr>
<td>Listen effectively to carers concerns, take on board and respect their comments and feedback</td>
<td>31</td>
<td>12%</td>
</tr>
</tbody>
</table>

(In the original report this is Table 17)

3. Professional perspective on information sharing

The original NIHR SDO research collected survey data from 212 mental health professionals. These were:

<table>
<thead>
<tr>
<th>Profession</th>
<th>CPN - 74 (35%)</th>
<th>Psychologist – 24 (11%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Work</td>
<td>35 (17%)</td>
<td>Occupational Therapy – 7 (3%)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>34 (16%)</td>
<td>Therapist – 7 (3%)</td>
</tr>
<tr>
<td>Other</td>
<td>31 (15%) [inc. GP, CMHT managers]</td>
<td></td>
</tr>
</tbody>
</table>

The new resource will target professionals working in adult services. Table 5, and the selected quotations below, summarizes the barriers identified by staff to working more effectively with carers.
### Table 5: Barriers to information sharing with carers supporting adults of working age

<table>
<thead>
<tr>
<th>Theme category</th>
<th>Number of professionals (n=173)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practical issues affecting professionals in relation to information sharing with carers</strong> (18 codes; range 1-46 cases)</td>
<td>122 (71%)</td>
</tr>
<tr>
<td>For example: consent, confidentiality rules, carer definition, uncertainty of diagnosis or prognosis – not knowing what ‘facts’ to share, impact on service user-professional relationship, balancing confidentiality vs. carer need to know, risk assessments.</td>
<td></td>
</tr>
<tr>
<td><strong>Key issues relating to service users</strong> (6 codes; range 1 – 37 case)</td>
<td>63 (36%)</td>
</tr>
<tr>
<td>For example: service user not wanting to share information (involve) carers, service user capacity, service user lack of awareness of benefits of sharing info with carers.</td>
<td></td>
</tr>
<tr>
<td><strong>Professional recognition of carer role</strong> (7 codes; range 1-32 cases)</td>
<td>58 (34%)</td>
</tr>
<tr>
<td>For example: lack of confidence (skills/ training) for working with carers, resistance to working with carers, lack awareness impact of information sharing on carer.</td>
<td></td>
</tr>
<tr>
<td><strong>Issues relating to carer (relative or friend) and wider family</strong> (14 codes; 1-13 cases)</td>
<td>52 (30%)</td>
</tr>
<tr>
<td>For example: relationship conflicts between carer and service user, understanding family dynamics, potential carer abuse, over involvement of carers, carers unwilling to be involved.</td>
<td></td>
</tr>
<tr>
<td><strong>Practical barriers</strong> (9 codes; range 1 – 28 cases)</td>
<td>50 (29%)</td>
</tr>
<tr>
<td>For example: lack of staff time to work with carers, difficulties arranging mutually convenient time for working carer and professional, difficulties accessing the carer, lack of space on wards for private time with carers.</td>
<td></td>
</tr>
</tbody>
</table>

(In the original report this is Table 21)

Professional recognition of the carer role, raised by 34% in the original survey sample of professionals as a barrier, will be directly addressed by the new resource. It is the driving factor behind generating the learning tool – to skill up staff to feel more confidence in addressing information sharing dilemmas. Each of the other barriers should also be referred to ensuring that the resource takes on board concerns from professionals, as well as difficulties experienced by carers.

"Patient alienated from carer following section / delusional system. Written consent from the patient is useless as they change their mind when ill - at exactly the time the carer wants to know what is going on”  (P21 Psychiatrist)
“Confidentiality makes it almost impossible for a clear open dialogue to be established. This is a detriment to all involved in the process and it hinders everything!” (P62 Psychiatrist)

“Consent is a major barrier also instinct in relation to the service users mental state” (P170 CPN)

“The main barriers are: patient consent; service protocols; communication method, e.g. telephone; determining level of carer; differentiating between direct carer and involved family; patient illness and behaviour, staff time” (P232 Social worker)

“Identifying what is confidential; ensuring you have consent; avoiding causing distress to carers” (P163 CPN)

“Uncertainty about the nature or cause(s) of the mental health problem (e.g. illicit drug use); uncertainty about the carer’s own mental health; uncertainty about the nature and stability of the carer’s relationship with the patient” (P24 Psychiatrist)

Table 6: Professional views on changes required to improve information sharing experiences for carers

<table>
<thead>
<tr>
<th>Solutions to improve working with carers:</th>
<th>No of responses (n=297)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer led actions</td>
<td>9 (3%)</td>
</tr>
<tr>
<td>Professional Led Actions:</td>
<td>137 (46%)</td>
</tr>
<tr>
<td>Related to changes in approach to working with carers</td>
<td>73</td>
</tr>
<tr>
<td>e.g. change attitudes to carers, involve carers (with consent), build open and honest relationships</td>
<td></td>
</tr>
<tr>
<td>Related to application of policies in routine clinical practice</td>
<td>24</td>
</tr>
<tr>
<td>e.g. regular reviews of consent, risk assessments, explain need for carer involvement to service user, awareness of carers to boundaries of confidentiality</td>
<td>40</td>
</tr>
<tr>
<td>Related to practical suggestions</td>
<td></td>
</tr>
<tr>
<td>e.g. Carer ‘surgeries’ staffed by professionals, three-way meetings, better communication, collecting consent routinely.</td>
<td></td>
</tr>
<tr>
<td>System changes:</td>
<td>151 (51%)</td>
</tr>
<tr>
<td>Provide training</td>
<td>51</td>
</tr>
<tr>
<td>Improve policy guidance notes</td>
<td>46</td>
</tr>
<tr>
<td>Provide services for carers</td>
<td>21</td>
</tr>
<tr>
<td>Improve educational resources available for carers</td>
<td>16</td>
</tr>
<tr>
<td>Address structural barriers e.g., workload pressures</td>
<td>12</td>
</tr>
<tr>
<td>Other e.g. management changes and health promotion emphasis</td>
<td>5</td>
</tr>
</tbody>
</table>

(In the original report this is Table 22)
“Firstly, carers need to be given the same respect for their confidentiality as is given to the patient and this urgently needs to be enshrined in law and guidance from DoH” (P168 Care centre manager)

“Training for professionals around issues of confidentiality. Professionals to listen to the experiences of carers either through training opportunities or carers assessments” (P58 Social worker)

“Clear protocols. More general information available to carers (e.g. written material about psychosis). Parent support groups. Establish information sharing agreement at start of treatment with all parties involved” (P45 CPN)

The original report also analysed data across all three stakeholder groups to compare views and preferences relating to different information sharing approaches. These data are reproduced in tables 7 and 8 below.

**Table 7: Approaches to overcome information sharing problems in mental health**

<table>
<thead>
<tr>
<th>Resolutions</th>
<th>Service user (n=154)</th>
<th>Carer (n=475)</th>
<th>Professional (n=212)</th>
<th>CSW (n=93)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional Actions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain to SU about their carers “need to know”</td>
<td>60% 77%</td>
<td>73%</td>
<td>89%</td>
<td></td>
</tr>
<tr>
<td>Discuss issue of confidentiality with SU and carer together</td>
<td>71% 74%</td>
<td>82%</td>
<td>88%</td>
<td></td>
</tr>
<tr>
<td>Share information with carer on a general (hypothetical) basis</td>
<td>32% 49%</td>
<td>44%</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>Help SU identify some aspects of their information they feel comfortable sharing</td>
<td>66% 56%</td>
<td>82%</td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Consider long term relationship between SU and carer before deciding whether to share info</td>
<td>54% 66%</td>
<td>58%</td>
<td>63%</td>
<td></td>
</tr>
<tr>
<td>Explore alternative ways of sharing info that are acceptable to SU (e.g. sharing with other closely involved person)</td>
<td>53% 45%</td>
<td>71%</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>Consent to disclose document of SU wishes</td>
<td>50% 52%</td>
<td>80%</td>
<td>74%</td>
<td></td>
</tr>
<tr>
<td>Make clear to carers the rules of professional codes by which they are bound</td>
<td>- 50%</td>
<td>77%</td>
<td>66%</td>
<td></td>
</tr>
<tr>
<td>In cases of series disagreement carers, SU and profs should be able to consult an officially recognised, independent group of people</td>
<td>44% 65%</td>
<td>63%</td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Support for carer / SU</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service user supported by advocate</td>
<td>47% 54%</td>
<td>77%</td>
<td>79%</td>
<td></td>
</tr>
<tr>
<td>Carer supported by CSW or advocate</td>
<td>36% 66%</td>
<td>73%</td>
<td>91%</td>
<td></td>
</tr>
<tr>
<td>Services</td>
<td>2009</td>
<td>2010</td>
<td>2012</td>
<td>2013</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>------</td>
<td>------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Carer supported through carers assessment</td>
<td>36%</td>
<td>59%</td>
<td>79%</td>
<td>80%</td>
</tr>
<tr>
<td>Carer supported by carer support network</td>
<td>37%</td>
<td>64%</td>
<td>79%</td>
<td>84%</td>
</tr>
<tr>
<td>Carer undergoes carer training</td>
<td>30%</td>
<td>52%</td>
<td>63%</td>
<td>75%</td>
</tr>
</tbody>
</table>

(In the original report this is Table 27)
Table 8: Service user, carer, professional and carer support worker rank ordered suggestions for overcoming information sharing in mental health

<table>
<thead>
<tr>
<th>Resolutions</th>
<th>Service user</th>
<th>Carers</th>
<th>Prof</th>
<th>CSW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explain to SU about their carers “need to know”</td>
<td>3 1 9</td>
<td>1 2 1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Discuss issue of confidentiality with SU and carer together</td>
<td>1 2 1 4</td>
<td>1 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Share information with carer on a general (hypothetical) basis</td>
<td>15 16 17 17</td>
<td>1 2 1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Help SU identify some aspects of their information they feel comfortable sharing</td>
<td>2 11 1 6</td>
<td>1 2 1</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Consider long term relationship between SU and carer before deciding whether to share info</td>
<td>4 5 16 15</td>
<td>1 2 1</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Explore alternative ways of sharing info that are acceptable to SU (e.g. sharing with other closely involved person)</td>
<td>5 17 11 16</td>
<td>1 2 1</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Consent to disclose document of SU wishes</td>
<td>6 13 3 11</td>
<td>1 2 1</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Make clear to carers the rules of professional codes by which they are bound</td>
<td>- 15 7 13</td>
<td>1 2 1</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>In cases of series disagreement carers, SU and profs should be able to consult an officially recognised, independent group of people</td>
<td>8 7 13 6</td>
<td>1 2 1</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

(Support for carer / SU)

| Service user supported by advocate                                        | 7 12 7      | 1 2 1  | 4    | 9   |
| Carer supported by CSW or advocate                                        | 13 5 9 2    | 1 2 1  | 4    | 2   |
| Carer supported through carers assessment                                 | 13 9 5 6    | 1 2 1  | 4    | 6   |
| Carer supported by carer support network                                  | 12 8 5 5    | 1 2 1  | 4    | 5   |
| Carer undergoes carer training                                           | 16 13 13 10 | 1 2 1  | 4    | 10  |

(In the original report this is Table 28)

These data are useful for the resource providing a level of consensus over practical solutions for professionals to try. The central tenant in all the work is that there are no blue print solutions, and complex factors to consider when decision making (context, nature of relationship, capacity, prior history, risk assessment) but that there are strategies that can be adopted rather than non-engagement based upon a ‘patient confidentiality’ shield. This information provided the starting point for developing the new resource. The main three key issues to address were: The collection of consent; Staff confidence for working with carers with regard to information sharing, in particular strategies to engage with carer without breaking patient confidentiality; Staff attitudes towards carers.
Appendix III: Discussion group information sheet

Information Sheet: Carers and Confidentiality Project
We would like to invite you to take part in a consultation group discussion for this project.

Background
The SDO funded project ‘Positive and Inclusive: Effective ways of mental health professionals sharing information with carers’ identified the importance of training professionals in good clinical practices. Professionals identified they lacked the confidence and skills to support carers through information sharing, balancing legal requirements and policy guidance with practical judgements when working with service users and their families. This current project seeks to develop a training resource appropriate to different mental health professional groups. This stage of the project is also funded by the SDO and is being carried out by Rethink with the guidance of an expert Project advisory group.

What is the purpose of the project?
The purpose of the project is to develop a training package for mental health professionals in order to help them to share information more effectively with carers.

The consultation discussion: what is involved?
We would like to ask you about the issue of information sharing with carers in general. We would like to ask you about what you feel would work best in terms of content and format for this training package. We would like to record this discussion in order for us to identify essential learning points that you feel would be useful to include in the training package.

Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

Contact Details
If you would like any further information about this project please contact:

Áine Duggan
Research Manager
Rethink

Postal Address:
5th Floor
Royal London House
22-25 Finsbury Square
London
EC2A 1DX

E-mail: Aine.Duggan@rethink.org

Phone: 020 7330 9139
## Appendix IV: Development Interview Guide

### Part One: Content

<table>
<thead>
<tr>
<th>General perception of information sharing with carers</th>
<th>Is this an issue that arises for you in your day to day working life? What guidelines do you currently follow? Trust policies/professional body policies etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Particular situations that have arisen</td>
<td>Examples of difficult situations that have arisen in the course of negotiating information sharing with carers</td>
</tr>
<tr>
<td>Possible content of training package</td>
<td>What topics would you like to see covered? Probe: Legal aspects, Case studies, Best practice. Helpful strategies</td>
</tr>
<tr>
<td>Opinions about outline package sent in advance</td>
<td>Topics covered</td>
</tr>
<tr>
<td></td>
<td>Level of detail</td>
</tr>
<tr>
<td>Target group</td>
<td>Explore idea of champions within teams</td>
</tr>
<tr>
<td>Explore feedback from carers about the issues of most importance to them</td>
<td>Place of carer as member of team Anxieties around lack of information</td>
</tr>
</tbody>
</table>

### Part 2: Format

<table>
<thead>
<tr>
<th>Experience of using training packages</th>
<th>Various formats that they have encountered Workbooks/E-learning/Face to face etc. Advantages/disadvantages of differing approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-learning training packages</td>
<td>Levels of competency in using such packages within teams</td>
</tr>
<tr>
<td>Format</td>
<td>Presentation of package Interactive features: audio/video etc. Module format</td>
</tr>
<tr>
<td>Timing issues</td>
<td>Length of time available for training Optimum length of training package</td>
</tr>
</tbody>
</table>
Appendix V: Script development

Each lesson went through a number of stages before the final version was settled upon. This appendix outlines the evolution of Lesson 3: Consent as a process

1) Initial idea

The idea that obtaining valid informed consent to share information with carers is not a ‘one off’ event but rather a process, is a key information sharing principle.

Feedback from carers and health professionals indicated that this was poorly understood. Given the importance of this issue it was decided to base a lesson around it.

2) Drafting of script

As outlined in Section 5 the drafting of the scripts for the filming of scenarios was an iterative process, with input from the project team, steering group, Rethink staff and external experts.

The initial script was drafted by the project team:

Initial script

Script:

CPN: Jodie, I spoke to your mother and she wanted to know how you are?

Jodie: You didn’t tell her anything did you, I don’t want to have anything to do with her..

CPN: I didn’t tell her anything but I think she is worried about you.

Jodie: Yeah well she has no right to get any information about me from you.

Option 1 for how the scene might continue:

Jodie: I don’t want her knowing anything about me, so don’t tell her anything.

CPN: Okay I’ll put that in the notes now that you don’t want anything shared with her at all.

Jodie: Good.
**Option 2 for how the scene might continue:**

CPN: Okay I understand where you’re coming from, but when she phones and she’s worried I think she just wants to know you’re safe. If I know that that is the case can I tell her that?

Jodie: What like nothing else, just that you’ve seen me and I’m okay?

CPN: Yes and maybe that you’re taking your medication and doing well?

Jodie: I suppose, but nothing else I don’t want her knowing where I’m living or who I’m seeing.

CPN: Okay that’s fine, I’m going to put that in your notes and if it’s okay with you we might talk about the sort of stuff you’re happy for us to talk to your mother about again soon.

Jodie: Well it probably won’t have changed but okay.

CPN: Thanks Jodie, that’s helpful.

Following the initial drafting of the scripts, they were circulated to the Rethink Workforce Development team, Rethink’s National Information and Advice service and the project steering group for feedback. This again was an iterative process and changes were implemented as feedback was received from these parties.

The script for Lesson 3 was changed to reflect more colloquial language and interaction. It was also changed to reflect good practice in negotiating the issues around consent to share information on the part of the health professional. The final script for Lesson 3 is shown below:

**Final Script:**

**Part 1: takes place in CPN’s office (video format)**

**CPN:** So Jodie, your Mum has been on the phone again wanting to know how you’re getting on?

**Jodie:** You didn’t tell her anything did you, I hate that woman I don’t want her to know anything about me, you know she had my driving licence taken off me don’t you?

**CPN:** I didn’t but I really think she’s just worried about you, she said you haven’t been in contact since that night you turned up when you weren’t well and ended up in hospital a few months back. She’s worried that you might not be very well again now.
**Jodie:** Yeah well when she rings I just hang up, I don’t want to talk to her and its down to me to say whether you can talk to her and I say that you cant.

**Option 1 for how scene might continue:**

**Jodie:** Look I just don’t want her knowing anything about me okay, so don’t tell her anything

**CPN:** Okay I’m going to document that in the notes now that you don’t want anything shared with her at all.

**Jodie:** Good.

**Option 2 for how scene might continue:**

**CPN:** Okay I understand where you’re coming from, but when she phones I think she just wants to know you’re safe. If I know that you’re safe is it okay for me to tell her that?

**Jodie:** What like nothing else, just that you’ve seen me and I’m okay?

**CPN:** Yes, just that I’m visiting you.

**Jodie:** I suppose yeah, but nothing else I don’t want her knowing where I’m living or who I’m seeing.

**CPN:** Okay that’s fine, I’m going to put that in your notes and if it’s okay with you we might talk about the sort of stuff you’re happy for us to talk to your mother about again later on.

**Jodie:** Well it’s not going to change but alright I suppose.

**CPN:** I think it’s when you’re unwell and you go to your mother’s house that she really needs some extra information to be able to do the best thing for you. Maybe we could just talk to her about your meds, and what would be the most helpful thing to do if you seem unwell?

**Jodie:** I suppose, but only what she needs to know to look after me and only when I’m staying with her.

**CPN:** Okay, understood, and that’s helpful so thanks.

**4) Building of lesson elements around script**

Following the development of the script, the lesson elements were built around it. This involved working closely with Minervation to develop ‘mock ups’ of what the lesson might look like.

It then involved working closely with the Workforce Development team and using the findings from the review of other e-learning resources to develop interactive lessons to engage users.

A paper version of the lessons which included features such as questions reflective tasks and other features was worked on in an iterative process by the project team, steering group and external experts. The lessons were
revised several times in this way. The outline below shows the early paper version of Lesson 3.

Lesson 3

Setting: Community- Service user speaks to care co-ordinator in Community Mental Health Team offices

Relationship between carer and service user: Mother/daughter

Mental health professional: Social worker

- Consent to share information should not be seen as a one off event, but rather as a process.
- All decisions about consenting to share information should be documented in patient notes.
- These decisions should be revisited at regular intervals to take account of changing circumstances in the service user’s life.

Context

Discussions between service users and mental health professionals about the sharing information with carers should not be a one off event. Rather, these discussions can be viewed as a process that are returned to and reviewed regularly.

Introduction

Jodie is living independently and is supported by a Community Mental Health team. Jodie has previously said that she does not want any information shared with her mother as they have had a difficult relationship in the past. When Jodie was unwell a year ago and still driving, her mother reported this to the DVLA and as a result Jodie’s licence was taken. Jodie has said that she doesn’t want her mother to be involved in her care in any way. When Jodie is unwell, she often turns up at her mother’s house and stays there intermittently. At these times the Jodie’s mother often phones the Community mental health team requesting specific information about her daughter’s condition. She has also asked to be involved in discussions around relapse warning signs and skills for handling her Jodie’s mood swings so she is better prepared when asked to help. In the following clip we see Jodie meeting with her social worker. Her social worker raises the issue of sharing information with her mother (who had phoned the social worker that morning to say that she spoke to her daughter by phone and that she thinks that her mental health is deteriorating and that it is likely she will turn up at her house in the near future).

Part 1: takes place in CPN’s office
SW: So Jodie, your Mum has been on the phone again wanting to know how you’re getting on?

Jodie: You didn’t tell her anything did you, I hate that woman I don’t want her to know anything about me, you know she had my driving licence taken off me don’t you?

SW: I didn’t but I really think she’s just worried about you, she said you haven’t been in contact since that night you turned up when you weren’t well and ended up in hospital a few months back. She’s worried that you might not be very well again now.

Jodie: Yeah well when she rings I just hang up, I don’t want to talk to her and its down to me to say whether you can talk to her and I say that you cant.

Question: What do you think the CPN should do next?

a) Document Jodie’s decision in the notes and move on (if this option is chosen, user should be directed to option 1 video clip)
b) Continue to probe about the reason for Jodie’s decision (if this option is chosen, user should be directed to option 2 video clip)

Option 1 for how scene might continue:

Jodie: Look I just don’t want her knowing anything about me okay, so don’t tell her anything

SW: Okay I’m going to document that in the notes now that you don’t want anything shared with her at all.

Jodie: Good.

Question: Can you think of anything else that the CPN could have done and considered in this situation?

Please watch option 2 video clip now.

Option 2 for how scene might continue:

SW: Okay I understand where you’re coming from, but when she phones I think she just wants to know you’re safe. If I know that you’re safe is it okay for me to tell her that?

Jodie: What like nothing else, just that you’ve seen me and I’m okay?

SW: Yes, just that I’m visiting you.

Jodie: I suppose yeah, but nothing else I don’t want her knowing where I’m living or who I’m seeing.

SW: Okay that’s fine, I’m going to put that in your notes and if it’s okay with you we might talk about the sort of stuff you’re happy for us to talk to your mother about again later on.

Jodie: Well it’s not going to change but alright I suppose.
**SW:** I think it’s when you’re unwell and you go to your mother’s house that she really needs some extra information to be able to do the best thing for you. Maybe we could just talk to her about your meds, and what would be the most helpful thing to do if you seem unwell?

**Jodie:** I suppose, but only what she needs to know to look after me and only when I’m staying with her.

**SW:** Okay, understood, and that’s helpful so thanks.

**Question:** What do you think of the manner in which the social worker approached the situation in Option 2? How would you approach a situation like this?

**Text tips**
- When a service user says that no information is to be shared with their carer it is worth exploring why they have decided this—what are their thoughts and concerns?
- In some cases, it may be that the service user is willing to share general information as in the case of Jodie above, once that is all that is shared.
- In the above scenario it is important to explore what is to be done regarding information when Jodie is with her mother.
- People may not want information shared for all sorts of reasons which may change over time.
- It is really important to view consent not as a one-off event but as a process, that should be reviewed frequently.
- The information that a service user is willing to share should be revisited at regular intervals, in case circumstances change.
- It is vital to document any particular references to information sharing with the carer(s) in the service user’s notes.

**5) Refining Lesson 3**

When this was built, the lesson was refined further in consultation with Minervation and other experts. For example, the language in the lessons was modified, the layout and controls were adjusted and additional interactive features such as ‘Actions for you and your team’ were added. The final version of this lesson can be viewed here: [http://rethinkdev.minervation.net/lesson/course.aspx?lesson=3](http://rethinkdev.minervation.net/lesson/course.aspx?lesson=3).
Appendix VI: Sample pilot instructions

Piloting of Rethink’s online carers and confidentiality resource

Background

Thank you very much for agreeing to take part in the piloting of Rethink’s online learning resource. The aim of this resource is to help mental health professionals to share information more effectively with carers, and to explore issues of confidentiality. It was developed with funding from the NHS Service Delivery Organisation and is based on research carried out by members of the project team (e.g. see Pinfold V, Rapport J, Bellringer S (2007) Developing partnerships with carers through good practice in information sharing. Mental Health Review, 12 (2): 7-14.)

What is involved?

We have developed an interactive course section, and this is the part of the resource that we would like you to try. Altogether, this whole process should take approximately 50 minutes and you can complete the course on any computer with an internet connection and Adobe flash player (this free programme comes as standard on most computers but if you need to download it, it can be done in two minutes here: http://www.adobe.com/shockwave/welcome/ or by contacting your IT department).

There are 3 short steps involved, please read all three before getting started.

1) To get started please complete this short survey:
   http://www.surveymonkey.com/s.aspx?sm=eZCA_2blank_2fSPeRHE_2f0P1Uw_3d_3d.

2) When you finish the survey you will be taken directly to the interactive course section, but if you have any difficulty reaching it, the website address is
   http://rethink.minervation.net/interactive-course.

3) When you have completed the course we would be grateful if you could complete a second short survey at:
   http://www.surveymonkey.com/s.aspx?sm=X_2fXntgBXSxG2lm0g_2f0_2b_2bGw_3d_3d.
   You will also find details of this web address on the interactive course page, but we include it here for reference.

Note: Even if you are unable to complete all of your allocated lessons we would be grateful if you could still complete the second survey.

Lesson allocation and unique code

We would like you to work through Lesson 1: Types of information, Lesson 2: Information sharing with fluctuating condition & Lesson 6: Carer adjusting to changing circumstances.

You will be asked for your unique code when completing the surveys. If you have received a numerical code directly from the project team please use this.

If you do not have a numerical code, please follow these instructions to generate your own unique code: Your code is simply your initials, followed by the day of the month on which your birthday falls. **So for example if your name is Tom Jones and your birthday falls on the 4th your code is TJ4.** All information that you provide will be held confidentially and will be seen only by the project team.
Note on video download speeds

For the purposes of the pilot the videos in the lessons have been set to take up to 20 seconds to load, to avoid further 'stopping and starting' while viewing the lessons on slow connections. I hope that this doesn't cause too much inconvenience.

Certificate of participation

If you would like to receive an e-mail certificate of participation, there is space for you to leave your details at the end of the survey.

Thank you very much once again for participating and please do not hesitate to contact me if you have any difficulty accessing the resource.

Best wishes,
Áine Duggan
Research Manager
Rethink
0207 840 3076/ aine.duggan@rethink.org
Appendix VII: Pilot survey - baseline

The survey was hosted on survey monkey. A copy is provided here.

Please complete this short survey before using the online learning resource.

1) Questions about confidentiality and information sharing

1. In the context of information sharing what is 'general information'?
   - Information that supports carers in their role without providing new specific details about the patient
   - New and specific information about the patient that was previously unknown to the carer
   - New and specific information about the patient of a sensitive nature that was previously unknown to the carer

2. Is the following statement true or false?
   - Informed consent is only valid if it is written, verbal consent does not count

3. When a patient does not want you to disclose any information to a carer which of the following is/are acceptable?
   - Speaking to the carer in general terms about the patient's condition without revealing new information
   - Speaking to the carer about the patient's recent change of medication
   - Offering the carer a carer's assessment and putting them in touch with a local carers' support group

4. Is the following statement true or false?
   - Patient confidentiality can only be broken in the best interests of the patient or the family, when the patient lacks capacity to give informed consent

5. Which of the following constitute evidence of informed consent to share information with a carer?
   - When the clinician says that the patient verbally agreed to allow the sharing of information with their carer
   - When the patient signs an advance statement allowing information to be shared with their carer
   - When the patient signs an informed consent form, stored with the patient notes stating that they allow information to be shared with their carer

6. In which of the following cases must the clinician break patient confidentiality and share information with the informal carer?
   - Where the clinician judges that there is a risk to the carer
   - Where the carer requests the information
   - Where the patient has previously consented to the requested information being shared even if this is no longer the case
   - When the carer is the 'nearest relative' and the patient is to be detained under Section 2 of the Mental Health Act (2007).
7. Is the following statement true or false?
   - If carers share information with the clinical team, this information should be treated in confidence and not disclosed to the service user without prior consent.

8. In a mental health care team who should take the decision whether to share information with an informal carer?
   - The patient's care co-ordinator (if applicable)
   - The member of the team who the carer requests information from in consultation with other team members
   - The team leader in conjunction with other team members
   - Any of the above

9. When a patient has signed an advance statement stating that if they become unwell they consent to sharing information with their carer, what should you do if they revoke this consent when they become unwell?
   - Respect that patient's current wishes and refuse to share information with their carer
   - Adhere to the advance statement and share information with the carer
   - Assess the patient's current capacity and base your decision whether to share information on this

10. In the context of information sharing, which of the following constitutes 'personal information'?
    - Information about the possible side effects of the patient's medication when it is already known that the patient is taking this medication
    - Information about discussions which took place between the patient and psychiatrist relating to the patient's views of the carer
    - Information about the patient's diagnosis when the diagnosis is already known to the carer

2) About you

We would appreciate if you could provide some information about yourself here. This information will be held confidentially. We gather it so that we can compile results across groups.

1. Are you?
   - Male
   - Female

2. In what setting do you work?
   - Community mental health team
   - Assertive outreach team
   - Early Intervention service
   - Acute setting
   - Other (please specify)

3. Your organisation—Do you work for:

4. What is your professional background?
   - Psychiatry
   - Nursing
   - Social work
5. Would you be willing to take part in a follow up telephone interview (lasting approx 30 mins at a time that is convenient for you) to give some further feedback on the online resource?

6. Would you like to receive a certificate (when the pilot project is complete) to say that you have taken part? You may want to use this for professional development purposes.

7. Please enter your unique code here.

If you have not received a code please enter your initials followed by the day of the month on which your birthday falls, e.g. if your name is Tom Jones and your birthday falls on the fourth day of the month, your code is TJ4.

We will ask you to use this code again in the second survey.
Appendix VIII: Pilot survey – follow-up

The survey was hosted on survey monkey. A copy is provided here.

Please complete this short survey after using the online learning resource.

1) Questions about confidentiality and information sharing

1. In the context of information sharing what is 'general information'?
   - Information that supports carers in their role without providing new specific details about the patient
   - New and specific information about the patient that was previously unknown to the carer
   - New and specific information about the patient of a sensitive nature that was previously unknown to the carer

2. Is the following statement true or false?
   - Informed consent is only valid if it is written, verbal consent does not count

3. When a patient does not want you to disclose any information to a carer which of the following is/are acceptable?
   - Speaking to the carer in general terms about the patient's condition without revealing new information
   - Speaking to the carer about the patient's recent change of medication
   - Offering the carer a carer's assessment and putting them in touch with a local carers' support group

4. Is the following statement true or false?
   - Patient confidentiality can only be broken in the best interests of the patient or the family, when the patient lacks capacity to give informed consent

5. Which of the following constitute evidence of informed consent to share information with a carer?
   - When the clinician says that the patient verbally agreed to allow the sharing of information with their carer
   - When the patient signs an advance statement allowing information to be shared with their carer
   - When the patient signs an informed consent form, stored with the patient notes stating that they allow information to be shared with their carer

6. In which of the following cases must the clinician break patient confidentiality and share information with the informal carer?
   - Where the clinician judges that there is a risk to the carer
   - Where the carer requests the information
   - Where the patient has previously consented to the requested information being shared even if this is no longer the case
   - When the carer is the 'nearest relative' and the patient is to be detained under Section 2 of the Mental Health Act (2007).
7. Is the following statement true or false?
   • If carers share information with the clinical team, this information should be treated in confidence and not disclosed to the service user without prior consent.

8. In a mental health care team who should take the decision whether to share information with an informal carer?
   • The patient's care co-ordinator (if applicable)
   • The member of the team who the carer requests information from in consultation with other team members
   • The team leader in conjunction with other team members
   • Any of the above

9. When a patient has signed an advance statement stating that if they become unwell they consent to sharing information with their carer, what should you do if they revoke this consent when they become unwell?
   • Respect that patient's current wishes and refuse to share information with their carer
   • Adhere to the advance statement and share information with the carer
   • Assess the patient's current capacity and base you decision whether to share information on this

10. In the context of information sharing, which of the following constitutes 'personal information'?
    • Information about the possible side effects of the patient's medication when it is already known that the patient is taking this medication
    • Information about discussions which took place between the patient and psychiatrist relating to the patient's views of the carer
    • Information about the patient's diagnosis when the diagnosis is already known to the carer

2) Your views of the course

1. Which lessons did you complete?
   1,2,3,4,5,6,7,8,9, I did not complete the lessons
   Any comments

2. Content
   • The content is easy to understand
     Strongly agree, agree, undecided, disagree, strongly disagree
   • The content of the lessons is relevant to me and my work
     Strongly agree, agree, undecided, disagree, strongly disagree
   • The content is pitched at the correct level for me
     Strongly agree, agree, undecided, disagree, strongly disagree

Please use the space below for additional comments on the content

3. Format
   • The lesson objectives were clearly stated
     Strongly agree, agree, undecided, disagree, strongly disagree
The material presented flowed logically
Strongly agree, agree, undecided, disagree, strongly disagree

The questions, discussion points and reflective tasks helped to keep me engaged
Strongly agree, agree, undecided, disagree, strongly disagree

I think that these lessons should be used by individuals
Strongly agree, agree, undecided, disagree, strongly disagree

I think that these lessons should be used by teams who work through them together
Strongly agree, agree, undecided, disagree, strongly disagree

Please use the space below for additional comments on the format

4. Interactive elements
- The lessons contained a good mix of interactive content
Strongly agree, agree, undecided, disagree, strongly disagree
- The video and audio content were easy to access
Strongly agree, agree, undecided, disagree, strongly disagree
- The video and audio content was engaging
Strongly agree, agree, undecided, disagree, strongly disagree
- The voiceover that featured on some of the lessons was useful
Strongly agree, agree, undecided, disagree, strongly disagree
- Being able to save my work in the lessons to download and print as a pdf, would be helpful
Strongly agree, agree, undecided, disagree, strongly disagree

Please use the space below to make any other comments about the interactive content

5. Did you explore the rest of the website?
If yes, please tell us what you thought about 1) the content and 2) the layout

6. Learning
To what extent do you feel that you learned from the interactive course?
Rating 1 to 5
Please indicate why you have given this rating

7. Please use the space below to tell us how we could improve the interactive course:
3) About you

We would appreciate if you could provide some information about yourself here. This information will be held in confidence.

1. Please enter the unique code (that you received via e-mail and also entered in the first survey) in the box below again.

Reminder: If you had not received a code we asked you to enter your initials followed by the day of the month on which your birthday falls, e.g. if your name is Tom Jones and your birthday falls on the fourth, your codewas TJ4.

After you have entered your unique code below, please complete questions 2-7 if you didn't answer them in the first survey.

2. Are you?
   - Male
   - Female

3. In what setting do you work?
   - Community mental health team
   - Assertive outreach team
   - Early Intervention service
   - Acute setting
   - Other (please specify)

4. Your organisation-Do you work for:

5. What is your professional background?
   - Psychiatry
   - Nursing
   - Social work
   - Psychology
   - Occupational therapy
   - Physiotherapy
   - Other (please specify)

6. Would you be willing to take part in a follow up telephone interview to give some further feedback on the online resource?

7. Would you like to receive a certificate (when the pilot project is complete) to say that you have taken part? You may want to use this for professional development purposes.
Appendix IX: Pilot interview schedule

Introduction (adapt as appropriate)

- Thank you very much for agreeing to take part in this interview, it is only with your input that we can improve the resource so we do really appreciate you taking the time.
- This project is a consequence of a piece of research conducted by Rethink with a number of academic partners on the issue of information sharing with carers.
- One of the recommendations that came from that study was that health professionals wanted more information and training on the issue of confidentiality and information sharing with carers. This is why we are developing this resource. It is funded by the National Institute of Health Research, Service Delivery Organisation programme.

<table>
<thead>
<tr>
<th>Content of interactive course</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the content relevant?</td>
<td></td>
</tr>
<tr>
<td>Do the lessons illustrate key learning points/information sharing dilemmas?</td>
<td></td>
</tr>
<tr>
<td>Is the content accurate?</td>
<td></td>
</tr>
<tr>
<td>Is the content up to date?</td>
<td></td>
</tr>
<tr>
<td>Are the lessons the right length?</td>
<td></td>
</tr>
<tr>
<td>Any general suggestions on improving the content?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Format of interactive course</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Were you able to access the course easily?</td>
<td></td>
</tr>
<tr>
<td>Were you able to access audio/video content?</td>
<td></td>
</tr>
<tr>
<td>Did Flash player work on your computer? (Probe for whether this was already installed/were they able to follow the link given on the pilot page to install/did they have to contact their IT department)</td>
<td></td>
</tr>
<tr>
<td>Where did you complete the course?</td>
<td></td>
</tr>
<tr>
<td>What do you think about the format and layout of the course? (Particularly for people who had difficulty accessing the video/audio content) would it be useful to have the course on DVD/CD ROM?)</td>
<td></td>
</tr>
<tr>
<td>Was there a logical order and flow of material?</td>
<td></td>
</tr>
<tr>
<td>Are the questions easy to understand?</td>
<td></td>
</tr>
<tr>
<td>Are they fair, and answerable from the information given?</td>
<td></td>
</tr>
<tr>
<td>Are they interesting?</td>
<td></td>
</tr>
<tr>
<td>Do they reinforce relevant learning points?</td>
<td></td>
</tr>
<tr>
<td>Is there appropriate feedback on the answers?</td>
<td></td>
</tr>
<tr>
<td>Do you think it is a good idea to be able to save the work you do in the course of the lessons and print it off along with the lesson content at the end (in pdf format)?</td>
<td></td>
</tr>
</tbody>
</table>
Did you explore the rest of the website?

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the information presented relevant to you?</td>
<td></td>
</tr>
<tr>
<td>What else would you like to have seen covered in these sections?</td>
<td></td>
</tr>
<tr>
<td>Do you have any suggestions as to how we can improve these sections?</td>
<td></td>
</tr>
<tr>
<td>Any other comments?</td>
<td></td>
</tr>
</tbody>
</table>

Learning

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel that it <strong>raised your awareness</strong> of the issue of information sharing with carers? (Check which parts they accessed i.e. just interactive course or also main site)</td>
<td>In what ways?</td>
</tr>
<tr>
<td>Has using the resource <strong>increased your knowledge</strong> of information sharing with carers?</td>
<td>In what ways?</td>
</tr>
<tr>
<td>Has using the resource <strong>increased your confidence</strong> in dealing with information sharing dilemmas?</td>
<td>In what ways?</td>
</tr>
<tr>
<td>Have you <strong>changed your practice</strong> in any way since using the resource?</td>
<td>How?</td>
</tr>
<tr>
<td>Do you feel that you have picked up <strong>any new skills</strong> from using the resource?</td>
<td>Any examples of this?</td>
</tr>
<tr>
<td>Do you think you will <strong>do anything differently</strong> in the future as a result of using the resource?</td>
<td>Tell me a bit more about this?</td>
</tr>
<tr>
<td>Who do you think this <strong>resource should be used by</strong>? e.g. teams working together, individuals?</td>
<td></td>
</tr>
<tr>
<td>What do <strong>Trusts</strong> need to do to support this implementation? e.g. add to mandatory training requirements?</td>
<td></td>
</tr>
<tr>
<td>Any general suggestions on improving raising awareness/skills development</td>
<td></td>
</tr>
</tbody>
</table>

Anything else you would like to cover that I haven’t asked about?
Appendix X: Usability testing

Introduction and screening questions

- “These usability tests are being conducted to help build the new Rethink Carers and Confidentiality website

- Rethink have commissioned Minervation to conduct usability testing on the site before it is launched.

- We will record the laptop screen and video the participants during the interview. These recordings will just be used in-house (to help us write our report) and shared with Rethink staff on a DVD.

- Your full name will not be used in the report we write.

- Could you briefly tell us:
  - Are you familiar with the existing Rethink website? (www.rethink.org)
  - How experienced are you at using the Internet?
  - How many hours do you spend online each day (excluding email)?
  - What websites do you regularly use to answer your health questions?
  - What makes a good health website?”

Additional test questions

These questions were selectively put to participants according to their relevance to the task and the current stage in the task.

1. Is the user able to easily accomplish their task?
2. Is the navigation user-friendly?
3. Is the content arranged in such a way that users are able to quickly and easily find the information they need (e.g. information about informed consent?)
4. What kind of information would you expect on this page if you clicked on that? Is there anything else on this page you might click on?
5. Is this what you would have expected?
6. What section are you in at the moment?
7. How would you get back to the page you were previously on?
8. What options on this page are good options to click?
9. Does this page contain everything you expect? What additional information would you require?
10. Are there any links on this page that you find of interest now you have completed your task?
11. How does the page make you feel? (i.e. is it text heavy and crowded or nicely laid out and clean?)
**User groups:** We tested 6 people: 4 Community Psychiatric Nurses, 1 Occupational Therapist and 1 Deputy Team Manager.

<table>
<thead>
<tr>
<th>Person 1</th>
<th>Group</th>
<th>Community Psychiatric Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Community Psychiatric Nurse</td>
<td>Over 30 years working as a CPN in London</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Has not used the Rethink website before</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Very little Internet experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Spends about 1 hour online each week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uses the Trust Intranet</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Values websites that are accessible and usable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Person 2</th>
<th>Group</th>
<th>Community Psychiatric Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Community Psychiatric Nurse</td>
<td>Has not used the Rethink website before</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Some Internet experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Spends about 3 hours online each week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uses the Trust Intranet and various charity sites (e.g. Mind and Sainsbury)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uses Google for specific questions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Values websites that are comprehensive with access to support group information, personal experiences and service provision information</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Person 3</th>
<th>Group</th>
<th>Occupational Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Occupational Therapist</td>
<td>Has used the Rethink website before</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Some Internet experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Spends about 1 hour online each day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uses NHS Direct and Google for health related searches</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Values websites - user-friendly with plain English</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Person 4</th>
<th>Group</th>
<th>Deputy Team Manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Deputy Team Manager</td>
<td>CPN who has now become a Deputy Team Manager</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Has used the Rethink website before</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Good Internet experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Spends about 2 hours online each day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uses a range of websites including the Department of Health, the Royal College of Psychiatrists, NIMHE, Mind, DirectGov and Go For Mental Health (a local site set up by service users in Westminster)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Values websites that are accurate, reliable, comprehensive, up-to-date and able to supply free publications (e.g. DH)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Person 5</th>
<th>Group</th>
<th>Community Psychiatric Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>C</td>
<td>Community Psychiatric Nurse</td>
<td>Has briefly used the Rethink website before</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Good Internet experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Spends about 1 hour online each day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uses NetDoctor and Google for health related searches</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Values websites that have up-to-date information with no commercial affiliations</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Person 6</th>
<th>Group</th>
<th>Community Psychiatric Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>C</td>
<td>Community Psychiatric Nurse</td>
<td>Has briefly used the Rethink website before</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Some Internet experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Spends about 1 hour online each week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Uses NHS Direct for background health knowledge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Values websites that are usable (clear navigation), engaging (colourful with images and big print) and lay friendly</td>
</tr>
</tbody>
</table>
User tasks

1. A client has just been referred to your team and you have your first meeting with him and his sister (who is his main carer) next week. You want to be able to help him to decide how he wants you to share information with his sister.

   Relevant material on the website:
   - Working with carers (all of it)
   - Good practice strategies > General strategies
   - Information sharing principles > Sharing information with carers: the dilemma
   - Information sharing principles > Types of information
   - Interactive course > Lesson 1 > Types of information

2. One of your colleagues has had a complaint against them for failing to share information with a carer where the carer was put at risk as a result. You want to ensure that something similar doesn’t happen to you in the future.

   Relevant material on the website:
   - Good practice strategies > General strategies > Assessment of care context
   - Information sharing principles > Professional judgement in individual cases
   - Working with carers > Overcoming barriers to carer involvement
   - Interactive course > Lesson 8 > Discharge from hospital

3. You are working with a family where relations have broken down between the service user and her husband. She does not want to have anything to do with her husband and doesn’t want you to talk to him and you are trying to work out some ways to support the whole family.

   Relevant material on the website:
   - Interactive course > Lesson 2 > Information sharing with fluctuating conditions
   - Working with carers (all of it but particularly: Working with carers > Some resources to share with carers)
   - Good practice strategies > When consent is withheld

4. You work in an inpatient unit and one of the patient’s mothers has phoned the ward wanting information about her son’s condition. You have seen in the patient’s notes that he has agreed to sharing general information with his mother and you want to ensure that you do not breach confidentiality.

   Relevant material on the website:
   - Interactive course > Lesson 1 > Types of information
   - Information sharing principles > Types of information

5. Your Trust is putting together a new Carers’ policy and you have been asked to put together an overview for the working group on the key points that should be considered when deciding whether to share information with carers.

   Relevant material on the website:
   - This is a catch all scenario so all of the site will be relevant
   - Information sharing principles (all of it but particularly > Key principles of confidentiality)
   - Good practice strategies (again all of this section is relevant)
   - Interactive course > all of it is relevant
Appendix XI: Revisions to resource post-pilot

The pilot and usability testing phases, identified a number of changes to be made to the resource. The table below details these changes, some of which have been carried out already and some which will be completed in due course. The edited version of the learning resource can be found at [http://rethinkdev.minervation.net](http://rethinkdev.minervation.net). Screen shots of the revised resource are also provided.

<table>
<thead>
<tr>
<th>A: Main edits for website sections from pilot</th>
<th>Suggested by</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Branding changes to website <a href="http://rethinkdev.minervation.net/home/">http://rethinkdev.minervation.net/home/</a>.</td>
<td>Rethink Public Affairs Team</td>
<td>To ensure that the website was recognisable as a Rethink branded website</td>
</tr>
<tr>
<td>COMPLETED</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) Clarification of why it is useful to share information with carers, addition of new section: <a href="http://rethinkdev.minervation.net/working-with-carers/benefits-of-involving-carers/">http://rethinkdev.minervation.net/working-with-carers/benefits-of-involving-carers/</a>.</td>
<td>External carers’ expert</td>
<td>To make explicit the benefits of good information sharing practices with carers</td>
</tr>
<tr>
<td>COMPLETED</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) Addition of glossary of terms to include: carer, next of kin and nearest relative: <a href="http://rethinkdev.minervation.net/working-with-carers/defining-carers/">http://rethinkdev.minervation.net/working-with-carers/defining-carers/</a>.</td>
<td>Participants in the pilot phase</td>
<td>To explain some of the key terms used in the site</td>
</tr>
<tr>
<td>COMPLETED</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) Addition of section on young carers: <a href="http://rethinkdev.minervation.net/working-with-carers/young-carers/">http://rethinkdev.minervation.net/working-with-carers/young-carers/</a>.</td>
<td>Carers, external representative from Carers’ organisation</td>
<td>To ensure that the role of young carers was acknowledged</td>
</tr>
<tr>
<td>COMPLETED</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) Addition of text on Carers’ rights to confidentiality: <a href="http://rethinkdev.minervation.net/information-sharing-principles/carers-right-to-confidentiality/">http://rethinkdev.minervation.net/information-sharing-principles/carers-right-to-confidentiality/</a>.</td>
<td>Feedback from participants in usability testing</td>
<td>To ensure that the issue of a carer’s right to confidentiality was made explicit</td>
</tr>
<tr>
<td>COMPLETED</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) Clarification of what is meant by ‘paid carers’ and inclusion of term ‘care workers’ as an alternative description: <a href="http://rethinkdev.minervation.net/working-with-carers/defining-carers/">http://rethinkdev.minervation.net/working-with-carers/defining-carers/</a>.</td>
<td>External carers’ expert</td>
<td>To make this term explicit as it has been known to cause confusion</td>
</tr>
<tr>
<td>COMPLETED</td>
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</tr>
<tr>
<td>7) Add reference to ‘Carers at the heart of the 21st century families and communities’</td>
<td>External carers’</td>
<td>This is an important reference to be made explicit</td>
</tr>
<tr>
<td></td>
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<tr>
<td>(2008):</td>
<td>expert included referencing as it does advances in carer policy</td>
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</tr>
<tr>
<td><strong>8) Add brief summary of key legislation rather than just links to further information:</strong></td>
<td>External carers’ expert</td>
<td>To give users of the resource a better idea of what will be found in the more detailed links</td>
</tr>
<tr>
<td><strong>9) Changes to language and punctuation in main website section</strong></td>
<td>Carers and mental health professionals</td>
<td>To ensure the resource is as accessible as possible</td>
</tr>
<tr>
<td><strong>10) Define LPAs in the section on Good Practice strategies:</strong></td>
<td>External experts</td>
<td>For completeness</td>
</tr>
<tr>
<td><strong>11) Acknowledgement of all relevant sources e.g. Princess Royal Trust as well as Royal college of Psychiatrists for partners in care campaign</strong></td>
<td>External expert from relevant organisation</td>
<td>To ensure that all resources are acknowledged correctly</td>
</tr>
<tr>
<td><strong>12) Revision of homepage to ensure it engages users on their first visit and revision of text to clarify the purpose of the resource</strong></td>
<td>Mental health professionals in course of usability testing</td>
<td>To ensure that this does not pose as a barrier to use</td>
</tr>
<tr>
<td><strong>8: Main edits for interactive course from pilot</strong></td>
<td>Suggested by</td>
<td>Rationale</td>
</tr>
<tr>
<td><strong>1) Inclusion of progress bar on videos</strong></td>
<td>External expert</td>
<td>To allow users to know the time left when watching videos</td>
</tr>
<tr>
<td>THIS IS A POSSIBILITY TO BE EXPLORED FURTHER WITH MINERVATION</td>
<td></td>
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</tr>
<tr>
<td><strong>2) Addition of subtitles for those who are hard of hearing or those who might have difficulty with sound on computers</strong></td>
<td>External expert</td>
<td>To allow further access to the resource</td>
</tr>
<tr>
<td>THIS IS A POSSIBILITY TO BE EXPLORED FURTHER WITH MINERVATION</td>
<td></td>
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</tr>
<tr>
<td><strong>3) Addition of downloadable pdfs with key learning points, scripts and participants’ work for all lessons</strong></td>
<td>Feedback from health professional participants in pilot, usability testing and external experts</td>
<td>To ensure that users of the resource have a record of their work and access to the salient points and strategies to refer to after completing the course</td>
</tr>
<tr>
<td>TO BE COMPLETED</td>
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<tr>
<td>Development of ‘myspace’ registration page: <a href="http://rethinkdev.minervation.net/login/?ref=/interactive-course/">http://rethinkdev.minervation.net/login/?ref=/interactive-course/</a></td>
<td>External experts, informal feedback from Rethink staff</td>
<td>To adopt a more conventional registration format</td>
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<tr>
<td><strong>5) Addition of voiceover to all lessons, to include on/off switch for sound</strong></td>
<td>Feedback from health professional participants in pilot</td>
<td>To give participants the option of listening to the voiceover if they find this feature useful, and the ability to ‘mute’ this function if it is not helpful for them</td>
</tr>
<tr>
<td><strong>6) Addition of new less ambiguous quiz questions for post course quiz and more immediate feedback on correct and incorrect answers</strong></td>
<td>Feedback from usability testing</td>
<td>A number of current quiz questions are ambiguous in nature and participants expressed the belief that it was difficult to choose the correct answer and that immediate feedback on what the correct answer was and why would be useful to their learning</td>
</tr>
<tr>
<td><strong>7) Revision of registration system to make it more user friendly</strong></td>
<td>Feedback from usability testing</td>
<td>To ensure that the registration system does not pose as a barrier to using the interactive course</td>
</tr>
</tbody>
</table>

**C: Specific lesson edits**

<table>
<thead>
<tr>
<th><strong>1) Lesson 1:</strong> In final suggestions, clarify that Ravi cannot forbid his psychiatrist from engaging with his mother</th>
<th>Feedback from pilot</th>
<th>For clarification purposes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2) Lesson 2:</strong> Add to ‘unhelpful’ points that the doctor should be giving (or signposting) the carer to further sources of information</td>
<td>Feedback from pilot</td>
<td>For clarification purposes</td>
</tr>
<tr>
<td><strong>3) Lesson 5:</strong> In suggestions, add the point that listening to the carer has revealed information that the mental health staff might not otherwise have had access to i.e. that the service user was pregnant</td>
<td>Feedback from pilot</td>
<td>For clarification purposes</td>
</tr>
</tbody>
</table>
4) Lesson 6: In the final suggestions further emphasis on the need to explore Ann’s concerns is warranted in case it is in fact the case that Rachel has unmet needs that have not been taken into account. Ann’s views should not be discounted.

TO BE COMPLETED

<table>
<thead>
<tr>
<th>Feedback from pilot</th>
<th>For clarification purposes</th>
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5) Lesson 8: In the background section perhaps change ‘general’ information to ‘personal’ information as this appears to be more accurate in these circumstances.

TO BE COMPLETED

<table>
<thead>
<tr>
<th>Feedback from pilot</th>
<th>For clarification purposes</th>
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</table>
A1: Branding changes to the web site

Pilot version: www.rethink.minervation.net

New revised version: www.carersandconfidentiality.org.uk
# Appendix XII: Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AMHP</td>
<td>Approved Mental Health Professional</td>
</tr>
<tr>
<td>BASW</td>
<td>British Association of Social Workers</td>
</tr>
<tr>
<td>BMA</td>
<td>British medical Association</td>
</tr>
<tr>
<td>BMJ</td>
<td>British Medical Journal</td>
</tr>
<tr>
<td>BPS</td>
<td>British Psychological Society</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
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<tr>
<td>CPA</td>
<td>Care Programme Approach</td>
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<tr>
<td>CPN</td>
<td>Community Psychiatric Nurse</td>
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<tr>
<td>CTO</td>
<td>Community Treatment Order</td>
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<tr>
<td>ESR</td>
<td>Electronic staff record</td>
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<tr>
<td>HTA</td>
<td>Health Technology Assessment</td>
</tr>
<tr>
<td>LD</td>
<td>Learning Difficulties</td>
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<tr>
<td>LPA</td>
<td>Lasting Power of Attorney</td>
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<tr>
<td>MCA</td>
<td>Mental Capacity Act</td>
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<tr>
<td>MHA</td>
<td>Mental Health Act</td>
</tr>
<tr>
<td>MH</td>
<td>Mental Health</td>
</tr>
<tr>
<td>MHAC</td>
<td>Mental Health Act Commission</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NIAS</td>
<td>National Information and Advice Service</td>
</tr>
<tr>
<td>NIHR</td>
<td>National Institute of Health Research</td>
</tr>
<tr>
<td>NR</td>
<td>Nearest Relative</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PPI</td>
<td>Patient and Public Involvement</td>
</tr>
<tr>
<td>RCN</td>
<td>Royal College of Nurses</td>
</tr>
<tr>
<td>RCP</td>
<td>Royal College of Psychiatrists</td>
</tr>
<tr>
<td>SCORM</td>
<td>Shareable Content Object Reference Model</td>
</tr>
<tr>
<td>SDO</td>
<td>Service Delivery Organisation</td>
</tr>
</tbody>
</table>
Disclaimer:

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health.”

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.