NHS England

Carer support and involvement in secure mental health services

A Toolkit

Start >

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uclan
University of Central Lancashire

Developing the toolkit

This toolkit has been developed by NHS England in partnership with UCLAN (The University of Central Lancashire). It has been co-produced by a steering group, involving a wide range of experience and expertise, most importantly carers themselves. In addition to the contributions of the steering group there has been wide involvement from a range of carers, service users, commissioners and service providers. The toolkit is based both on previous research, including a recent Scottish Study (Ridley et al. 2014), and a new study into how carers' needs are met within secure services in England. A separate report outlining the results of this new study has also been produced.

The accompanying short films were similarly produced using participatory methods, led by the Flexible Films team who are film-makers with lived experience of mental health care.

Foreword

The five and a half million carers in England make a critical and underappreciated contribution not only to loved ones, neighbours and friends but to the very sustainability of the NHS. To make this contribution, carers often make great sacrifices to support the people they look after. The NHS Five Year Forward View committed the NHS to find new ways to support and empower carers, including the most vulnerable.

Although more needs to be done to recognise and support carers in general, those who come into contact with secure mental health services (forensic carers) have slipped under the radar and often do not even receive the support that is given to prisoners' families. Carers of people in secure services have often experienced very traumatic times, with many going through the criminal justice system first, and some carers being the victim of their loved one. Many forensic carers report not feeling valued, not being given information and not being involved or listened to by professionals. This has prompted forensic carers to fight for the right services, and for services to share information when given the opportunity, and support family relationships.

NHS England's Commitment to Carers applies just as strongly for forensic carers as to other carers. Families are important to recovery and carers often hold information that allows services to work more effectively. Because carers are often traumatised by the admission of a loved one to secure services, early identification and an effective carer health and wellbeing assessment are even more crucial. This toolkit is built on lived experience and

aims to empower carers to navigate the system. The principles set out here should also be common practice in secure settings. Carers will still be there when secure services are no longer required and it is vital for them to be supported from the word go as valued partners in care.

This is a generic toolkit which is aimed at meeting the needs of all carers. However we are aware that Black, Asian and Minority Ethnic (BAME) people are disproportionately at risk of being detained in secure mental health settings and in custody. Key facts, information and data can be found in the Race Disparity Audit, the Government's Ethnicity Facts and Figures website and the Lammy Review. We will therefore be undertaking further work around the needs of BAME carers in the future.

Neil Churchill

Director for Participation and Experience

Foreword

For the first time, it feels as if a light has been shone on carers with loved ones in secure services. We have been in the dark for far too long; often unknown, ignored and undervalued whilst challenging the Criminal Justice System in the midst of a mental health crisis, and then continuing to support our family members and friends for many difficult years.

The toolkit was co-produced with professionals, carers and service users, who were all passionate about not only giving guidelines to commissioners and service providers, but raising the profile of forensic carers generally. We wanted the individual stories of forensic carers to be heard, the trauma and distress they feel to be recognised and the problems they are facing to be acknowledged so that lessons can be learned and changes made as a result.

This toolkit is a sign of hope for the future. We hope it is a beginning for more carer engagement, clear recognition of our worth and that services will see the importance of involving us throughout the care pathway.

Most importantly, for carers themselves, we hope we have used our experiences to enable them to better understand secure services so they feel more confident in their journey through them. With this confidence and information, we also hope that carers are empowered to challenge services if they do not reach their expectations. It is right and proper that we do now have clear expectations of secure services and a vision and commitment for how these can be met.

Sheena Foster
& Sue Stewart

Working with carers, friends and families of people in secure mental health services
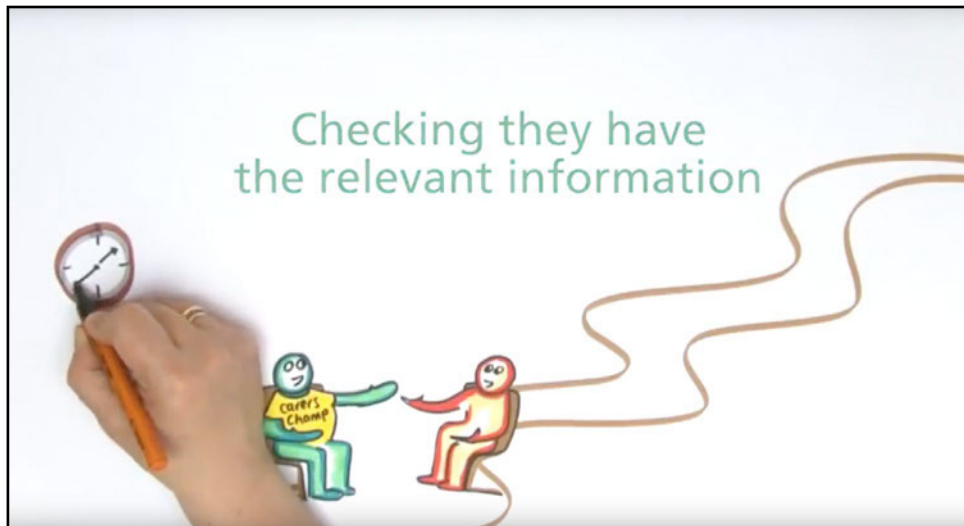
Part 1

Part 2

Contents

I would say it is a mixed blessing. Lots of stress and tears at times but also I get a lot out of being able to provide support. I also learn a lot about mental health and myself, my capabilities. I think I am a better person for it.

Carer

Introduction

This toolkit aims to provide clear information for carers, service users, service providers and commissioners about how carers of people who use secure mental health services should be engaged with, supported, involved and empowered.

Although this toolkit primarily focuses on secure inpatient settings it could apply to other parts of the secure pathway.

It is vital that services recognise what carers want and their need to be involved in three main ways:
1. They have their own needs as carers around information and support.
2. They want to be involved in the care of their loved one.
3. They want to be involved in service developments, training and improvements.

The toolkit links to an extensive range of resources, practice examples and advice that will support staff, commissioners, providers and carers. It highlights what carers should expect from services. It can also be used to improve how commissioners and providers can engage and involve carers to better meet their needs and the needs of their loved ones. Within the toolkit we include some of the many practice examples that were identified by carers and providers, to highlight different ways of working with carers in secure settings. We hope by highlighting some of these examples we will encourage interested people to make contact and learn from each other, enabling further work in this area.

It is important that adult secure services respond to carers appropriately. Carers should be treated in culturally appropriate ways, where appropriate, taking account of needs associated with their culture, language and faith. However, it is important not to make assumptions about what needs someone may have. The support and involvement of carers should also take account of other relevant protected characteristics, those related for example to age, disability, gender reassignment and sexual orientation etc. Some carers will also wish to advocate on behalf of their relatives and will expect to see the provision of culturally sensitive services and positive, appropriate and sensitive responses to their relative's needs, for example, related to age, disability, gender reassignment and sexual orientation. Policies and procedures addressing the care of service users should equally apply when working with carers within these services.

The toolkit aims to:

- Empower carers by supporting them to understand what they should expect - identifying key questions to ask at different points, providing examples of practice to show what is possible, and improving understanding of the secure mental health pathway and the responsibilities of different professionals and services.

- Empower service users to ask questions and challenge practice in relation to their carers. They should expect to be supported to have fulfilling relationships with their family and friends as much as they would wish.

- Empower commissioners by being clear about what carers should expect. Commissioners can make reference to the toolkit in commissioning intentions, planning and service specifications. This will ensure carers are involved in meaningful ways and ensure that contracts improve support and involvement of carers.

- Empower service providers by providing information that contributes to what a good service looks like, providing examples of practice that can develop an approach to engaging with, supporting and involving carers.

Background and context

Who are carers?

Secure mental health services exist at different levels of security. There are a number of different terms used to describe carers of people who use secure mental health services. In this toolkit we talk about 'forensic carers' or simply 'carers' to describe relatives and friends who play a role in the care of those who use secure mental health services. We use these terms in relation to unpaid carers. The idea of being a carer 'at a distance' fits with this definition of a carer from (Department of Health 2008: 53):

"An individual who provides or intends to provide practical and emotional support to someone with a mental health problem. They may or may not live with the person cared for".

I thought I wasn't a carer. and no-one said 'of course you are'.

Carer

A forensic carer role:

This caring role can be quite wide-ranging, including:

• Providing individual support such as:
  - giving practical help
  - offering emotional support
  - providing a check on reality
  - offering help to understand and obtain rights
  - maintaining contact with other family members or friends
  - assisting with securing legal services and other information
  - advocating for their relative or friend with services or external agencies.

• Relating and connecting to services, such as:
  - being a point of contact
  - involvement in care planning, case review or risk assessment and management
  - helping services be more aware of triggers to ill-health
  - assisting with discharge arrangements, such as securing accommodation.

• Keeping in contact, such as:
  - visiting, phone calls, and other means such as online communication or video messaging
  - within restrictions, bringing in practical items
  - providing financial support.

Forensic carers have their own needs for information, support and involvement. In turn, meeting these needs will bring benefits for service user care and outcomes as well as for services. Whilst issues of confidentiality can be complex these need not be seen as a barrier to effectively and meaningfully involving and supporting carers.

I am not looking after him as he's an adult and he's in a secure unit but I'm his only family. In that sense I am a carer, I'm one of the only people who cares about him at all.

Carer

Key principles

"It's just obvious to me. We are his family. Who could know him better than us? Who other than us would want to care for him more?" **Carer**

Through the work to develop this toolkit we have identified some key principles for meaningful involvement and support for forensic carers:

1) The support and involvement of carers within secure mental health services, and recognition of a duty of care to carers themselves, should be prioritised by service providers and commissioners.

   "The views of families, carers and others where appropriate should be fully considered when taking decisions. Where decisions are taken that are contradictory to views expressed, professionals should explain the reasons for this." Mental Health Act Code of Practice principle.

2) All aspects of care planning, case review, and risk management are open to carer involvement if the service user wants this. If the service user does not want this then general information can still be given that enables continued carer support.

3) Carers should have timely access to appropriate and relevant information and their questions answered with candour.

4) Services and commissioners should proactively ensure that carers have access to emotional and practical support. This includes recognising the range of experiences and complex circumstances that carers may experience; and ensure this informs the support they provide. This includes experiences carers may have had on the journey into secure care.

5) Engaging with forensic carers should be recognised as everyone's job. Staff should have the skills, knowledge and capacity to support and involve carers. Training and support should be offered to ensure all staff are able to carry out this role.

6) Carers have a key role in the care of their loved one and should be involved if they wish and the service user also wants this. Services have a role in supporting service users and carers to re-establish relationships with each other if they have broken down and those involved want support with this.

7) Carers should be involved in the design, planning and improvement of services.

Research findings

We conducted surveys of carers and services
What forensic carers tell us

Key findings

• Carers may have been victims. They may need support to understand why their relative or friend has been admitted to secure services or help to understand the behaviour of their loved one.

• Many carers have experienced difficulties maintaining relationships with their loved one in the secure service. For some, the breakdown of family contact begins in advance of admission to secure care.

• An important but relatively neglected aspect of family life that can be hugely disrupted by admission to secure services is for those service users who are parents. Contact with children can be lost, often, but not always, for safeguarding reasons. In the long term, such separations can exacerbate mental health problems and lead to lengthy, complicated and stressful journeys to reunite families. Within extended families, the effects of such separations can touch the lives of all family members, some of whom may find themselves taking on a new parenting role.

• Carers in secure services are often no different to carers in other health service contexts. They want to act upon caring relationships, to be involved and supportive, even though they may need help to accomplish this effectively. The involvement of carers will aid recovery and reduce the risk of their loved one reoffending.

• Carers have expressed that they would like their views brought to the attention of service providers as 'carers' concerns' and would like an appropriate and accountable response from services.

A more detailed account of the research study can can be found on the University of Central Lancashire (UCLAN) website.

Carers are individuals with skills, knowledge and experience that can make a positive impact on their relative or friend's care and treatment. Carers can provide information about skills, managing behaviour, information about what works and what does not, medication history, key life events and reflections on how these have contributed to the circumstances leading up to the admission of their loved one to secure services. This information should be seen as vital to the recovery of their relative or friend.

What service providers tell us

Key findings

Providers told us about many examples of efforts to improve the support and involvement of carers. This toolkit contains some practice examples found in this study and the wider literature. However, we did not identify many services that appeared to have a clear and comprehensive approach to supporting and involving carers.

- The most commonly identified measure was the provision of information packages. Including those tailored to individuals in a variety of formats e.g. video, face to face.

- Staff who take up dedicated roles for carer support enjoy the work and experience high levels of job fulfilment. However, there is a danger that a specific role can limit the support from other staff as they may assume it is already covered. Where carers are most thoroughly supported and involved there is evidence of a more systematic approach.

- Staff also report difficulties negotiating the complexities of information sharing about patient care, and challenges dealing with colleagues over issues and assumptions about confidentiality. Staff would like more support and training for colleagues to better understand and work with the nuances of confidentiality and information exchange.

Working to provide better services for carers can be hard work but it is the right thing to do. When we get this right, everybody wins. Carers feel better supported and involved, they are then better at providing support to their relative, the patient. And we find out what families know which makes our job of patient care easier and more effective. It is a virtuous cycle when we do this well.

Carers' Lead

- Staff described how they were impressed with the resilience of some carers despite challenging events and circumstances, including the obstacles to visiting, such as distance from home.

- Staff are frustrated when they think too few carers take up offers of involvement or support groups. The majority of services report some difficulties engaging with carers particularly where there is minimal contact.

- The research has highlighted many imaginative ways that services are trying to improve their engagement with carers, including organising welcoming events and use of digital technologies to keep in contact at a distance.

- Many services signpost carers to alternative forms of support, for their own practical and emotional support needs. This includes, on occasion, access to independent carers' advocacy services.

- A growing number of services are working to enhance carers' knowledge of mental health and illness and care and treatment approaches.

- Services are beginning to involve carers at a more strategic level, as are commissioners. In some regions, there are emerging attempts to do this in ways that involve networks of carers from different units.

Assessment (before admission)

Before admission to secure services, carers will often have been in contact with other services in primary or secondary care including GPs and/or acute mental health wards or community teams. Carers often have information that can support these services and early contact can offer opportunities to prevent or minimise future risk.

Assessments and support for the service user and carer may be provided by local authorities under the Care Act (2014). The Triangle of Care provides a framework for ensuring that carers are appropriately and adequately supported and involved.

Many service users arrive at secure services after contact with the police and a journey through the courts and possibly prison. These experiences can be uniquely challenging and stressful, even traumatising, for carers. Particular problems can be experienced when carers are also victims and wish to remain in contact with the service user. Institutional barriers to involvement can leave carers feeling helpless, for example, if they want to ensure their loved one is receiving appropriate treatment. Media coverage of cases can also be particularly distressing for carers.

...You wouldn't believe it. I couldn't get anyone to take me seriously. Not his GP, not even the psychiatrist he eventually saw. It wasn't until one of them was assaulted that things swung into action.

Then I was told he was a big risk. Like I hadn't been saying this all along!

Carer
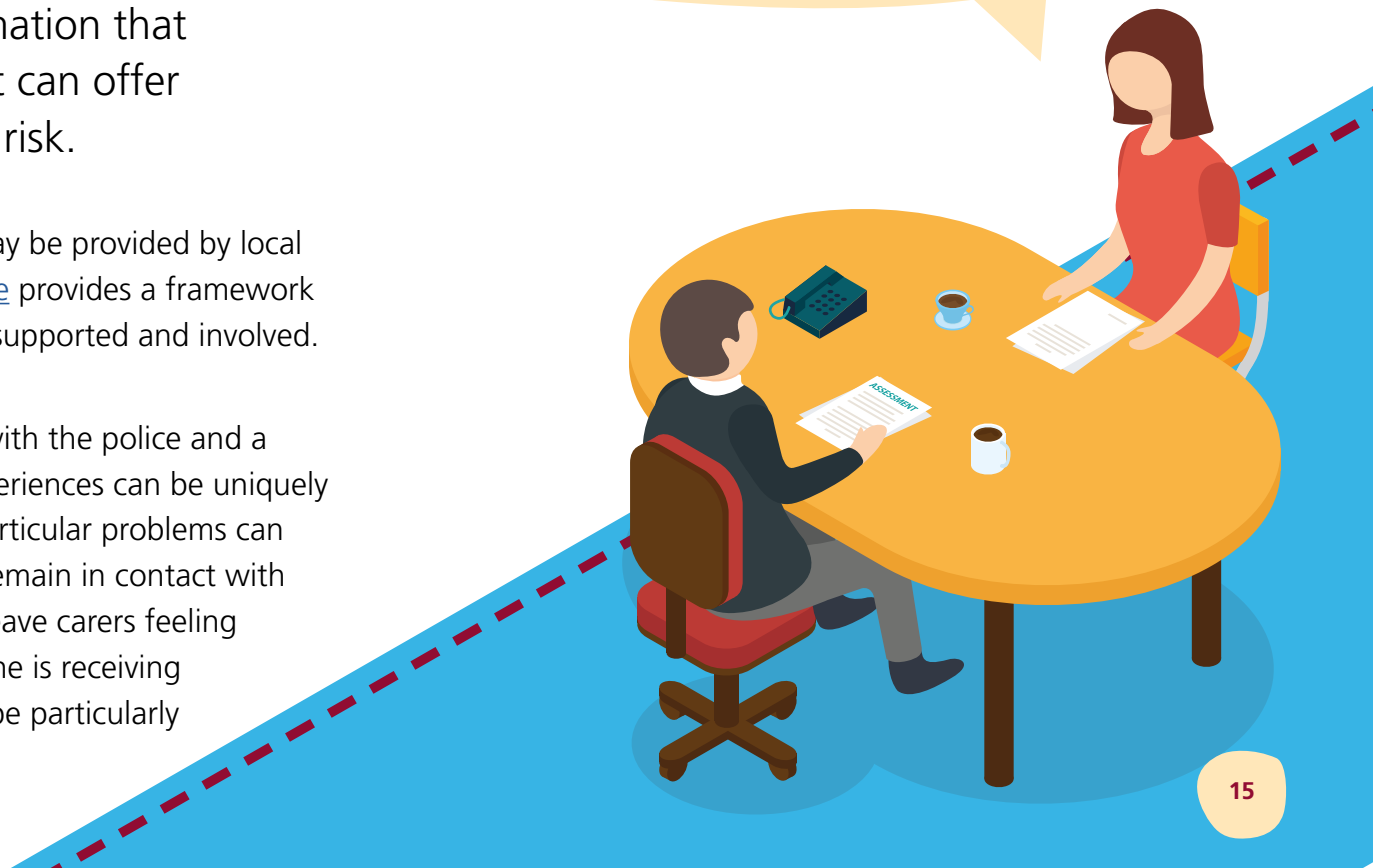
This section highlights the experiences that carers may have been through before coming into contact with secure mental health services.

Police custody and courts

For those carers whose relative or friend is arrested for an offence and processed through the courts this can be a stressful time when they really need support. There can be a double stigma attached to mental health and involvement in the criminal justice system.

Carers can be victims of offences, such as serious assault or murder. Such circumstances can adversely affect wider family relationships, which may require help to repair. Carers can and do wish to continue to support the service user going forward, but can face procedural barriers to maintaining contact.

The practicalities of dealing with police or the courts can also be highly stressful. For many carers, it may be their first experience of dealing with the criminal justice system, and legal language and procedures can be confusing.

There may also be practical issues dealing with domestic arrangements, such as accommodation/tenancies and other aspects of personal circumstances that are disrupted by arrest/remand/sentencing. Some carers may act as 'appropriate adults' during police interviews and have rights under the Police and Criminal Evidence Act. If a person is mentally vulnerable, a carer has the right to be an appropriate adult and present during interviews if the person under arrest wants them to take this role.

I really needed support at the time, but didn't get any. I was really on my own. Other family didn't want to know. Because I was the victim I couldn't speak to my son, but I was very, very worried about him. This went on for ages. I really don't know how I coped.

Carer

Prison

Carers can experience stress and anxiety when their relative or friend is sent to prison. Carers can fear for the safety of their relatives or friends; this includes fear of assault by other prisoners or staff. These anxieties are compounded by an appreciation of an individual's vulnerability, perhaps exacerbated by ongoing mental distress and associated worries that they will not be getting the best care and treatment for mental health problems. They can be faced with having to get a Mental Health Act assessment while their relative is in prison. Other problems for carers can include travelling long distances to visit and the stigma of having a relative or friend in prison.

Assessment for admission to secure care services

Admission to secure mental health services will usually follow an assessment process, where a forensic psychiatrist and other multi-disciplinary team colleagues will meet with the service user – in prisons, or in lower levels of security. At this stage, carers will value involvement, to alleviate anxieties or receive information about the new service, for example, visiting arrangements. Assessors should try – where it's ethical and practical – to liaise with carers before the service user is admitted to a secure service.

Carers may be entitled to a carer's assessment under the provisions of the Care Act (2014). Carers can have different needs based on their circumstances. A carer's assessment will assess these needs and oblige local authorities to provide relevant support depending upon meeting eligibility criteria. Such support might include assistance for a carer's own health and wellbeing needs or help with travel. It is worth noting that visitors to service users detained for an extended period may not necessarily be deemed a carer under Care Act definitions, until the point that the service user is about to be discharged into the community.

Key resources

NICE (National Institute for Health and Care Excellence) Two relevant sources of information provided by NICE:
Guideline: Mental health of adults in contact with the criminal justice system
Pathway: Health of people in the criminal justice system

Rethink Mental Illness provide a series of Criminal Justice Guides including for point of arrest, courts, prison and secure hospital.

Centre for Mental Health This mental health and criminal justice document identifies key areas for improvement in the system.

Royal College of Psychiatrists Standards for mental health care in prisons developed by the Royal College of Psychiatrists. Standards for prison mental health services

Mental Health, Autism and Learning Disabilities in The Criminal Courts This document was published jointly by Rethink Mental Illness and the Prison Reform Trust. It gives helpful information to magistrates, district judges and court staff, explaining how they can recognise people who appear before them with specific communication needs, so that the court can make a proper assessment of the case and its outcome. The information and links in the document will be helpful to many carers in these situations.

The Carers Trust This organisation supports carers and promotes the desirability of involving carers in health care services.

The Care Act (2014) This legislation places a duty on the local authority where the carer resides to offer a carer's assessment.

Admission to secure care

Coming into the visitors' centre is such a difference. The staff are just brilliant. Friendly and kind. They smile and always make time for you. I can't tell you how much difference this means to me.

Carer

When their relative or friend is admitted to a secure mental health unit, carers will have various needs for information, support and involvement. If services and care teams recognise the value of supporting and involving carers, both in terms of addressing carers' needs and the potential for better supported families to be an asset in enhancing the care to service users, then this needs to be reflected in a set of welcoming and inclusive practices. The fact that carers are welcomed must be evident from the very beginning. The involvement of carers may not be completely straightforward, as staff in services have to manage complex issues of capacity and consent of service users.

WELCOME

A welcoming approach

It is important to get the initial first contact right. A welcoming attitude that is communicated to carers in a way that explicitly values early and ongoing involvement is important to cultivate and build trust.

Some service users will not wish their relatives or friends to be involved, or care teams may assess that the service user lacks the capacity to make this decision. In such circumstances, services should have contact with carers to discuss the constraints on communication and provide general information that does not breach patient confidentiality. There should be a commitment to a regular review of any decision by service users to exclude carers from involvement.

Keeping in contact

"The distance from the hospital and my work make visiting difficult. Then I feel bad about not coming enough." **Carer**

It is important for services to build upon their welcome, and support carers who wish to maintain contact with their loved ones. Stresses and strains within relationships may make it difficult where service users and carers want to keep in touch. The opportunity to talk about any difficulties with key staff can provide reassurance, help come to terms with changed circumstances, or assist carers to repair relationship problems.

Providing information

"I just wanted someone to talk to, I didn't understand about forensic services, it's been a massive learning curve for me. To start with I felt like a failed parent, I was very different, I was sad and upset, I've moved on now." **Carer**

Carers appreciate and need good quality information. Services can produce comprehensively written information packs and use different media, such as videos showing the interior of the unit where the carer's relative or friend will be living. Relevant information will include practicalities of visiting the hospital, knowledge about mental health and treatments, and details of how carers can get more involved.

Balancing involvement and confidentiality

"The confidentiality issue has to be sorted out because so much is hidden behind it." **Carer**

Sharing information can also provide an opportunity to discuss matters of confidentiality, without closing down possibilities for involvement. Negotiating the limits of confidentiality can be a complex process of balancing a service user's rights with their carer's interests. On occasion, confidentiality can operate as a justification for not sharing information and effectively excluding carers. There is often a minimal need for this to be the case. Service users do not have the right to prohibit a professional from engaging with a carer, or giving carers general information, advice and support.

Though information provided or discovered in the course of a professional relationship cannot be disclosed without a person's consent, professionals are not necessarily prevented from talking to carers about facts they already know: a breach of confidentiality only occurs when professionally held information is newly disclosed.

Best practice involves an ongoing process of checking a service user's views on who to share what information with. Hence, an initial refusal for services to share information should not necessarily be seen as the final word.

The importance of information exchange is expressed in the quote from a carer member of the Reference Panel that opens the Mental Health Act Code of Practice (CoP):

"Everyone including carers and families need to know about the Code and all communication channels - from bottom to top and vice versa including sideways - should remain open for the benefit of all."

Forensic carers will have needs of their own that services can meet without service user confidentiality being an issue. That said, it is often the case that the most important issue affecting carers and their emotional well being is concern about the welfare and progress of their loved one – the service user.

Staff in secure services can be worried about breaching legal obligations. Legally, carers can be given general information about the condition of the person cared for, though not specific information if the service user does not consent. Information sharing with carers is also subject to the requirements of the Data Protection Act 2018.

The law makes a distinction between carers and nearest relative. The service user's nearest relative has certain rights to be given a range of information about the service user's detention under the Mental Health Act. However, these rights are not absolute and information should not be shared with the Nearest Relative if the service user does not want it to be. More generally, carers have no specific rights or roles given to them by the Mental Health Act. The importance of carers, however, is now recognised in the Mental Health Act Code of Practice for England (2015). The relevant section says that carers should be involved in decisions about care and treatment where the service user wishes or if the service user lacks the capacity to understand.

The Mental Capacity Act (2005) states that carers should be consulted by professionals in assessing a service user's capacity for making decisions, when it is reasonably practicable to do so. If a person lacks the mental capacity to make a decision, carers should be involved in working out what is in the person's best interests.

Valuing carer involvement in the care process

The admission period is a time when care teams are assessing individuals with a view to tailoring the most appropriate care package. Forensic carers are well positioned to provide helpful information to contribute to this assessment and settling in process. They may have important information that contributes to history taking, including insightful recollections of key times in the life and early experiences of the service user. Also, information about a person's personal characteristics, preferences and quirks, either associated with mental health difficulties or not, can be very helpful. This needs to be done at a pace that is right for the carer.

The admission period can also be a time when carers are in need of emotional support, including access to therapy of their own. In extreme cases, they may have been victimised and may be involved in a Serious Incident review.

What carers should expect: support and involvement at admission

1. Staff are welcoming and warm in their interactions with carers. This would include opportunities for carers to tell their own story and be asked about their own needs.

2. Staff receive training about the value, rights and needs of carers.

3. Clear information is provided to carers. This should be:
   - Practical information that they can take away and read at their own pace – to enable contact with hospital and service user.
   - Clear that the organisation values the role and contribution of carers.
   - Displayed prominently in an area that carers can access.
   - Informative about supporting carers to visit and maintain contact with their loved one (for example, by telephone and in person).
   - Accessible and take into account diverse communication needs.
   - Informative about facilities for virtual visits – using digital technology for maintaining contact between relatives/carers and care teams.
   - Co-produced with carers and service users.

4. Carers are given a named contact at the earliest opportunity and are offered a face to face induction meeting (or telephone meeting if this is more suitable for the carer) close to the point of admission, plus ongoing contact thereafter. This should include provision of key information that helps carers familiarise themselves with the unit, cope with stresses they may experience at this time, and tells them what to expect.

5. Services should, wherever possible, signpost carers to alternative forms of support, for their own practical and emotional need for example independent carers' advocacy services.

6. Services should have a clear confidentiality and information sharing protocol for carers which is positive and proactive and seeks to engage and involve carers wherever possible.

Practice examples

Within the toolkit we include some of the many examples that were identified by carers and providers, to highlight different ways of working with carers in secure settings. We hope by highlighting some of these examples we will encourage interested people to make contact and learn from each other, enabling further work in this area.

Ashworth High Secure Hospital, Mersey Care NHS Foundation Trust. Carers have use of a Welcome Centre – a bespoke facility next to the hospital entrance that carers can access before or after visits. This is comfortably furnished and has tea and coffee making facilities. There is a designated person to welcome carers on their visits to the hospital. The centre hosts a six weekly programme of carers' forums, which include psychosocial education sessions for carers. These are coordinated and facilitated by a senior social worker/carers lead. The forum has a clear terms of reference that was co-produced by carers and the carers lead. Carers are supported with practical issues such as form filling. A variety of helpful information is on display. Service users' artwork and home-made greetings cards are displayed and can be purchased.

Contact person:
Amanda McBride - Senior Forensic Social Worker/Carer Lead
[I/S]

The Spinney Hospital, Elysium Healthcare.
Carers are given a 'virtual tour' so they can better understand and appreciate the setting where their relative or friend will be cared for. The virtual tour is recorded on a DVD which is available to all friends and relatives. The DVD was developed by service users, carers and staff and provides a glimpse of patient life at the Spinney. It includes a guided tour (photographic) around all areas of the hospital so that carers of service users can see the Spinney (inside and out) before they visit. The DVD is sent out with a visitors' pack to carers when service users are first admitted. Feedback has been positive, with reports that the DVD alleviates some of the worry of having a relative or friend admitted to a secure hospital.

Contact person:
Beverley Beckett - Lead Social Worker
[I/S]

Broadland Clinic, Hertfordshire Partnership Foundation Trust

The social worker visits carers before and after admission. All service users have a carers' contact care directive - an agreement between service user, carers and a named nurse about the level of contact they would like (i.e. weekly, monthly).

The service aims for contact with carers every two weeks. There is also a carers' group.

The first point of contact with carers is during the period prior to admission. The social worker sends out an introduction letter with a booklet about the service. The family are then contacted by phone in order to arrange a visit. The service believes this shows its respect for carers and acknowledges their importance in individuals' recovery. Purposely, this contact is organised so as to not take up time when carers are visiting. This is particularly important if they have had to travel great distances. People are far more relaxed in their own home, on a 1-1 basis, and therefore able to ask questions without feeling they are too trivial.

The visits give the social worker an opportunity to explain key issues, such as specific sections of the Mental Health Act (MHA). Many carers are so focused on immediate concerns whilst court cases are going on, about the person possibly going to prison, that they may not have asked or do not recall what the implications are under the MHA. Carers receive information about the meetings they will be invited to, including who will be there and what their role is, so they know what to expect. Most have had difficult experiences of attempting to get help, so the opportunity to share information and vent frustrations is appreciated. There is also the chance to talk about difficulties that brought their loved one to secure services. The social worker checks if carers need financial assistance or support and signposts them to available resources and services, as many carers are traumatised in their own right.

For organised carers' days, the focus is set by the group. Carers decide which professional they want to hear from and what topics they want more information about. The service also organises a lunch for service users and their friends/relatives so they can share a meal. The carers' group is currently helping to set up a local carers' charter ensuring participation in the development of the service. Home visits for service users can be arranged for carers unable to travel.

Contact person:
Rose McCloskey - Forensic Social Worker
[I/S]

Links to key resources

NICE Guideline: Transition between inpatient mental health settings and community or care home settings. Provides general information about transitions in a secure mental health service context.

Providing information
Department of Health: Information sharing and mental health. Provides general guidance on information sharing by mental health services, most of which is relevant to secure mental health services.

Valuing carer involvement in the care process
Triangle of Care. Produced by the Carers Trust, this guide to best practice in involving carers in mental health services is a key document for leading practice change and stating key principles.

Further information and resources can be found via the Carers Trust website.

NICE Guideline: Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services. This general guidance has relevant information about the value of supporting and involving carers and has links to other relevant documents. The guidance clearly states that carers should have the chance to be involved in decisions about care and treatment.

Care in Secure services

Carers experience a range of ongoing stresses in relation to secure services. This includes being faced with Care Programme Approach (CPA) meetings, Care and Treatment Reviews (CTRs), carer's assessments, tribunals, ward changes, meeting psychiatrists, ongoing communication, seclusion, restraint and medication. Services and care teams can take various steps to alleviate this stress. Ideally, the supportive information and efforts to build relationships outlined in the previous sections will help to build resilience and ensure that carers have the information they need.

I worry about my son. It is real mental anguish not being able to help him too much with this. It is reassuring to meet staff who appear able to help him and then to see him make progress. The main thing that carers want to know about is that the person they care for is well looked after. Everything else comes second to this.

Carer

Establishing trust

A positive effect of a welcoming atmosphere for carers is the potential to build trusting, meaningful relationships. Reported negative experiences by carers include a perception that they are not trusted by staff, or even feeling blamed for their loved one's predicament. The sense of not being trusted is made worse if security approaches are oppressive, or matters of confidentiality and service users' best interests (as deemed by the care team) are communicated unsophisticatedly or insensitively.

Support for the stress of being a carer

"Most dealings with staff focus rightly on my son but I don't get much chance to get help with my issues. In many ways, it is all linked. I am better able to support my son if I feel better." **Carer**

Carers experience multiple stresses. These can include the stress of dealing with their loved one, understanding complex mental health problems, making sense of an offence and the complexities of responsibility or blame. Carers also experience a great deal of stress in navigating the system and in their dealings with services and care team staff. They can also be stressed by stigma, media coverage and even hostility within their home communities and neighbourhoods. All of this can adversely affect both the emotional and physical wellbeing of carers. A key reason for supporting carers is that they are better placed to support service users if they are healthy themselves.

Attending to particular disability and special needs

Relatives of particular groups of service users may have substantial problems ensuring their loved ones receive appropriate care or support in the secure care sector, and this generates equally particular stresses and grievances for carers. This could include carers of service users diagnosed with learning disability, autism, with sensory impairments, or those who have problems with alcohol or substance use. These matters can be exacerbated if specialist services or knowledge within secure services is lacking and the carer is required to navigate additional or different services.

Support around visiting

"Lots of the time I have felt a mixture of not knowing what to do or say when I meet him. I get stressed out and upset when I see he has been suffering. Afterwards, I am exhausted and feel ill myself. I can't sleep or eat properly. It's terrible." **Carer**

Forensic carers and service users can experience heightened stress at visiting times. Both can worry about what to talk about and whether certain subjects, such as mental health, the offence, or progress through the system, are off-limits – leading to stress and avoidance. Alternately, visits can be stressful because service users are uncommunicative for other reasons, such as low mood or tiredness, which may be medication related. In these circumstances, carers can struggle to keep a conversation going.

Meeting ongoing information needs

Carers have ongoing needs for information, including general information about the service and specific details about their loved ones, and their progress through the system.

Carer involvement in care review and strategic planning

Carers welcome involvement in aspects of case management and care planning and are positioned to make a valuable contribution to these processes. Carers are invited to all ward rounds and CPA meetings at some units. In other places, invitations are limited to the less frequent but more focused CPA meetings. Where young people or adults with learning disabilities who exhibit challenging behaviour are concerned, carers might be invited to be part of Care and Treatment Reviews (adults) and Care, Education, and Treatment Reviews (children and young people).

Psychosocial interventions and family therapy

There is a growing body of research that shows the value of psychosocial approaches, but they are not universally available in secure settings. These psychosocial interventions can be organised using digital/remote technologies to involve carers who live a distance from services and this digital delivery is highly appreciated.

Identified staff roles supporting forensic carers

"It would have been good to have a member of staff whose job is just focused on relatives and gets to know them well to support them. There are some very good staff but some don't seem to have the time for families." **Carer**

Services should have dedicated staff focused on carer support, who are the point of contact for carers. This benefits carers and also provides a fulfilling role for staff who know they are making a difference. Such personnel can take an overarching role – providing direct support to carers, facilitating involvement practices, and promoting a culture of valuing carers across the service.

Maintaining contact with forensic carers

It is important that there is an ongoing positive relationship between the care team and carers. This will also help strengthen contact between carers and their relative or friend. Carers in the study reported mixed experiences of their loved ones being supported to be present at family events such as weddings, funerals or birthdays.

Carers' support groups

Staff in provider services have a role in signposting to other services and places for carers to get information and support. Carers' peer support groups have long been advocated as important for facilitating support and involvement. These groups provide mutual support between carers that begins with the recognition of shared experiences. Support groups can take various forms – they may be facilitated by professional staff or self-organised by carers, or a mixture of the two.

What carers should expect - support and involvement in secure settings

1. Secure settings should have a coordinated approach to support and involvement. Specific activities would include organising carers' groups and events, signposting carers to support groups nearer to home, and ensuring that policies for carer involvement are developed in partnership with carers and service users. These policies should cover the value of carer involvement in all aspects of care, including risk assessment and management.

2. Dedicated member(s) of staff who support carers and coordinate service responses. Actual roles and numbers of such staff will depend upon the size of particular units. The objective of the staff is to facilitate direct communication with care teams. The existence of identified roles does not preclude all staff having an interest in supporting and involving carers.

3. Secure services should develop visiting arrangements to ensure that:
   - Staff are trained to minimise the intrusive impact of safety and security procedures.
   - Skilled staff are on hand at visiting times to help talk through any specific upset or stress.
   - Visiting times are seen as a possible opportunity for therapeutic engagement where this is appropriate, and for staff to introduce themselves to carers.

- Briefing and de-briefing sessions are offered for carers who find visiting times problematic.
- There are up to date picture boards of the staff team with a brief explanation of roles.

4. Services should highlight when they can provide specific support for carers who are victims or signpost to another appropriate service. For these and other carers, options should include forms of psychosocial intervention and family therapy (where appropriate), which can be delivered face to face or using digital technology.

5. Carers should be routinely involved at relevant points of care, potentially including Care Programme Approach (CPA), ward rounds, care planning and review meetings, including Care and Treatment Reviews (CTRs). Efforts should be made to work around the availability of the carer.

6. Systems are in place and documented for maintaining contact with carers, for example in relation to the frequency of contact or responses to phone calls. This should include a provision that carers' concerns are adequately recorded, to ensure accountability for responding to such concerns.

7. Support for service users to maintain active contact with family and friends, for example attending family occasions within the scope of leave restrictions.

Practice examples

Within the toolkit we include some of the many examples that were identified by carers and providers, to highlight different ways of working with carers in secure settings. We hope by highlighting some of these examples we will encourage interested people to make contact and learn from each other, enabling further work in this area.

Ashworth High Secure Hospital, Mersey Care NHS Foundation Trust.
A comprehensive information resource provided in different media formats (written and video). Tours of the hospital are also available to relatives or friends prior to and following admission. There is an information video for carers who can expect follow up contact up to 72 hours after their relative's admission. The hospital has a dedicated child contact suite; a child contact DVD is available to families and can be requested prior to an approved child contact visit.

In the written information pack itself, there is:
- A statement of a service user ethos that is appreciative of involving carers and acknowledges their needs e.g. a commitment to Triangle of Care principles and carers' rights under the Care Act.
- A simple statement of who the information is for; defines a carer – inclusive of family and friends.
- Information about the hospital and levels of security.
- A therapeutic ethos and details about the range of therapies and activities available.
- Key phone numbers and emails, especially those relating to visits and care team members.
- Specific information about bespoke services or staff for supporting or involving carers.
- Travel directions; and support for travel expenses.
- Information encouraging carers to keep in touch with the service user and/or care team, and different ways to do this.
- Details of the best time to speak with different care team members.
- Information regarding useful contacts such as advocacy or Patient Advice and Liaison Service (PALS), or external mental health or support organisations.
- Information about special facilities – welcome centre, arrangements for children visiting, possibilities for virtual visits.
- Information on visiting times and requirements/practicalities for planning/arranging visits.
- Information on safety and security, with a brief explanation of rules that apply to visitors.
- A simple statement regarding confidentiality issues: with a service user's consent clinical information can be shared with carers. Where a service user withdraws consent, general information about the hospital, its service provision as well as education about mental ill-health and recovery is still available to carers.

Contact person:
Amanda McBride - Senior Forensic Social Worker / Carer Lead
[I/S]

Cheswold Park Hospital, **Riverside Healthcare.** Family and friends are invited to events and the service hosts meals and visits to the ward. The hospital also provides financial support to help with the cost of visiting. Web pages provide information for carers, with the option to take a virtual tour, showing the interior of the hospital. Carers are provided with a resource pack about the hospital, visiting, meetings at the hospital, what to expect as a carer and direct telephone numbers of the service user's named nurse and dedicated social worker. Social workers are available during office hours to speak with carers and ensure their views and opinions are heard within the service user's wider clinical team. Care teams view contact and partnership with carers as crucial to a service user's recovery and this extends to encouraging involvement in care planning. The aim is for carers to feel empowered and involved. Social workers based at the hospital take responsibility for supporting contact by both telephone and visiting to best suit the needs of carers. The Social Work Team consults with carers to provide reports for tribunals and hospital managers, in order to identify the views of the nearest relative and any possible risk issues.

Carers are invited to quarterly dining events to share an evening meal with their loved ones in the hospital's main dining room. There is also an annual weekend event and tour of the secure areas of the hospital. This helps carers to understand care and treatment at the hospital.

Contact person:
Kathryn Crossley - Social Work Clinical Team Leader
[I/S]

North West Boroughs Partnership NHS Foundation Trust. All carers are given a Matron Card, credit card sized information with contact details for local matron. This is backed by an invitation to 'ask 3 questions'. These resources are also available as leaflets. The cards are given to all service users and carers and the leaflets are posted with all CPA invites. They were developed in conjunction with AQuA (Advancing Quality Alliance) and the Right Care Shared Decision Making programme, as part of the 2015/16 CQUIN (Commissioning for Quality and Innovation) target.

Service users and carers are encouraged to ask questions of services. Three particular questions are suggested:
• What are my options?
• What are the pros and cons of each option for me?
• How do I get support to help me make a decision that is right for me?

Service users are encouraged to involve family or friends in questions and decisions.

Contact person:
Sue Lee - Modern Matron Specialist Services
[I/S]

30

West London Forensic Service, West London Mental Health NHS Trust. The Trust employed a consultant systemic family therapist in 2004 with the remit of developing family therapy across the secure service. Family therapy is now available to all service users in the men's and women's secure inpatient wards, the adolescent secure inpatient unit and the Forensic Outreach Service. Currently, there are two half-time family therapy posts, one in the adolescent service and one in the adult service. In addition, in the adult service, a clinical psychologist trained in family therapy has five sessions of her post dedicated to carer therapy. The team has developed 'welcome meetings', in which carers are invited to meet the multi-disciplinary team (MDT) shortly after their loved one has been admitted. Welcome meetings evolved from a wish to establish a carer inclusive practice on the adolescent unit. They proved so effective in reducing conflict and increasing understanding and collaboration between carers and professionals, in support of the young person's recovery, that they were – eventually extended to the adult service, where they also proved successful. Welcome meetings have since been adopted by other secure services and became a CQUIN target for all adolescent inpatient services for 2016/2017.

The welcome meeting is held as near as possible to the point of admission, in order to address the family's immediate concerns and establish positive relationships from the start. The meeting brings together staff, service user, carers and anyone seen to be significant in the service user's social network. One of the family therapy team acts as a facilitator,

making sure the service user's and carer's questions, concerns, suggestions and requests can be voiced; and inviting different members of the MDT to respond. Welcome meetings are given structure by using a number of key questions (addressed to service user and family):

- What do you need to know about the hospital and what happens here? What's most important to you?
- What do we need to know while we are looking after you/your loved one (e.g. special needs or difficulties, talents or interests, goals in life)?
- While you are/your loved one is here, is there anything you would like us to pay attention to or help with?
- How are we all going to keep in touch (service user and carer; carer and professionals)?

The team has written a number of publications about their work and have featured in the Quality Network for Forensic Mental Health Services – MSU Newsletter.

Contact person:
Jo Bownas – Family Therapist
[I/S]

St Andrew's Hospital, Northampton. The Family Support Service (FSS) was established in September 2016. Its remit is to promote and support carer involvement in the care and treatment of adults with a learning disability, to ensure better outcomes for service users. A range of support services includes helping carers to understand a service user's difficulties or diagnoses, and explaining the different treatments offered within the Learning Disability Pathway. The service also meets with carers to share the different coping or 'crisis' strategies that their loved one is learning in therapy sessions and, where appropriate, to discuss wider aspects of therapy. The FSS also offers Behavioural Family Therapy (BFT) – a set of sessions for service users and carers to attend together to learn skills around communication and problem solving, to understand the needs of the service user and to promote positive relationships. This is supported by a colourful leaflet that explains the FSS and BFT.

Carers are encouraged and supported to attend ward rounds and wider care planning meetings. It is recognised that it is not always easy for carers to attend meetings in hospital, so carers are also seen in their own homes. The team has found that seeing people in their own homes improves relationships with services and helps carers recognise that the team's involvement with them is a genuine investment in a better future for their loved one.

Contact person:
Deborah Morris – Consultant Clinical Psychologist
[I/S]

Links to key resources
Attending to particular special needs
NICE Pathway: Mental health problems in people with learning disabilities. This document from NICE indicates a model care pathway for this client group. It has a clear statement of rights of carers to assessment, support and advocacy.

NICE Quality Standard: Autism
This builds upon the Autism Act (2009) and the need for local authorities to develop effective strategies for the health and social care services for individuals with autism. The quality standard is expected to be used alongside other NICE guidance to inform commissioning and improve quality of existing services. In this sense, the quality of care extends to carers.

Carers' involvement in care review and strategic planning
ImROC Briefing: Making recovery a reality in forensic settings. This document is published by ImROC - Implementing Recovery through Organisational Change. It is focused on recovery oriented practices in secure mental health services and makes the case for effective involvement of carers. Indeed, supporting connections with relatives, friends and the wider world is stated as the most important foundation for individual hopefulness and recovery.

Secure Services CPA standards

These are standards for the conduct of CPA meetings that have been co-produced. They put the service user at the heart of the process and value carer involvement. This ought to involve being supported to send out letters in the name of the service user inviting relatives or friends to CPA meetings.

Carers of young people or adults with learning disabilities who exhibit challenging behaviour may also have the opportunity to take part in specific review processes. These are called Care and Treatment Reviews (adults) and Care, Education, and Treatment Reviews (children and young people).

Carer focused education and support

NICE quality statement says carers of adults diagnosed with psychosis should be engaged in education and support programmes.
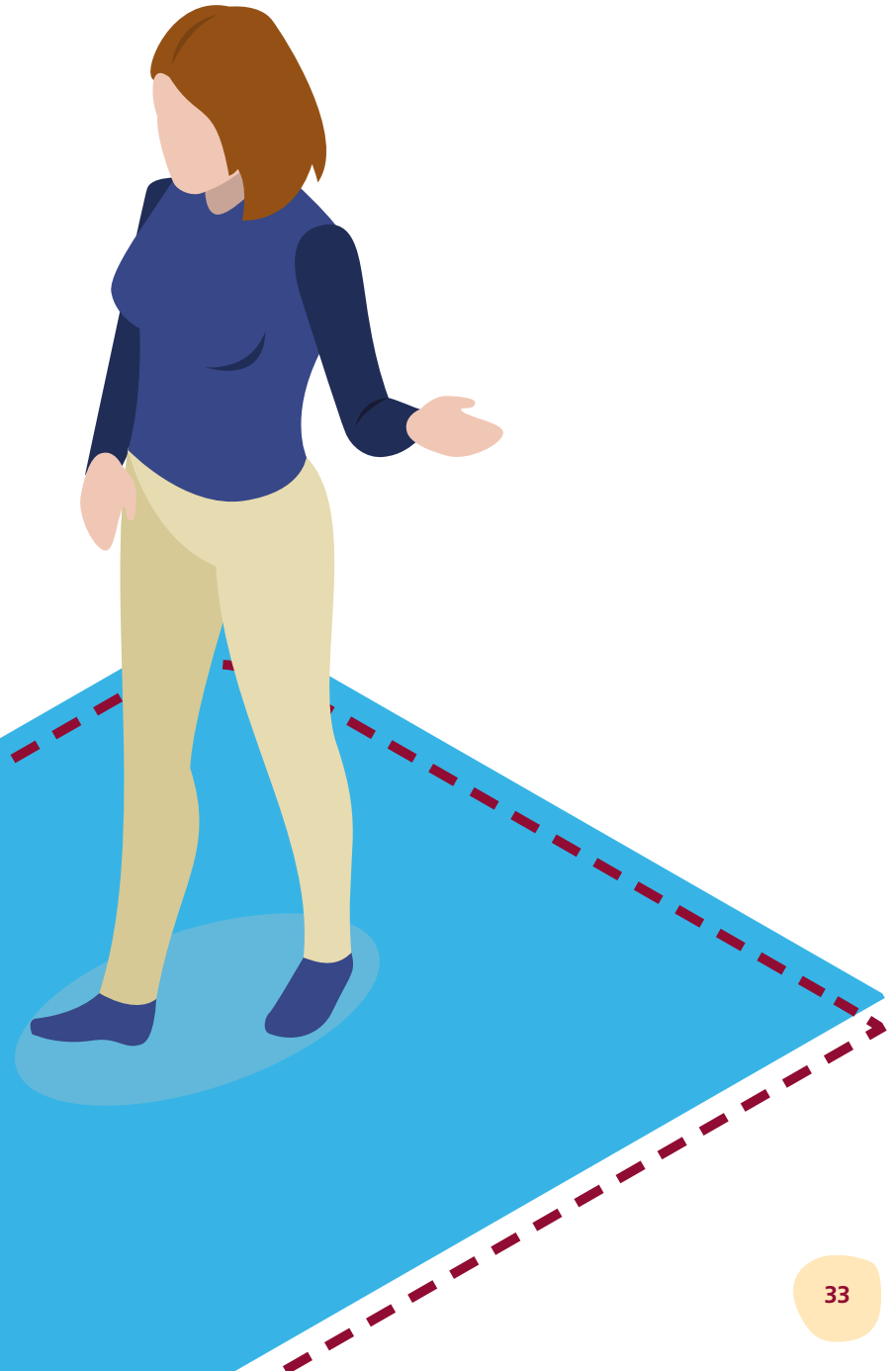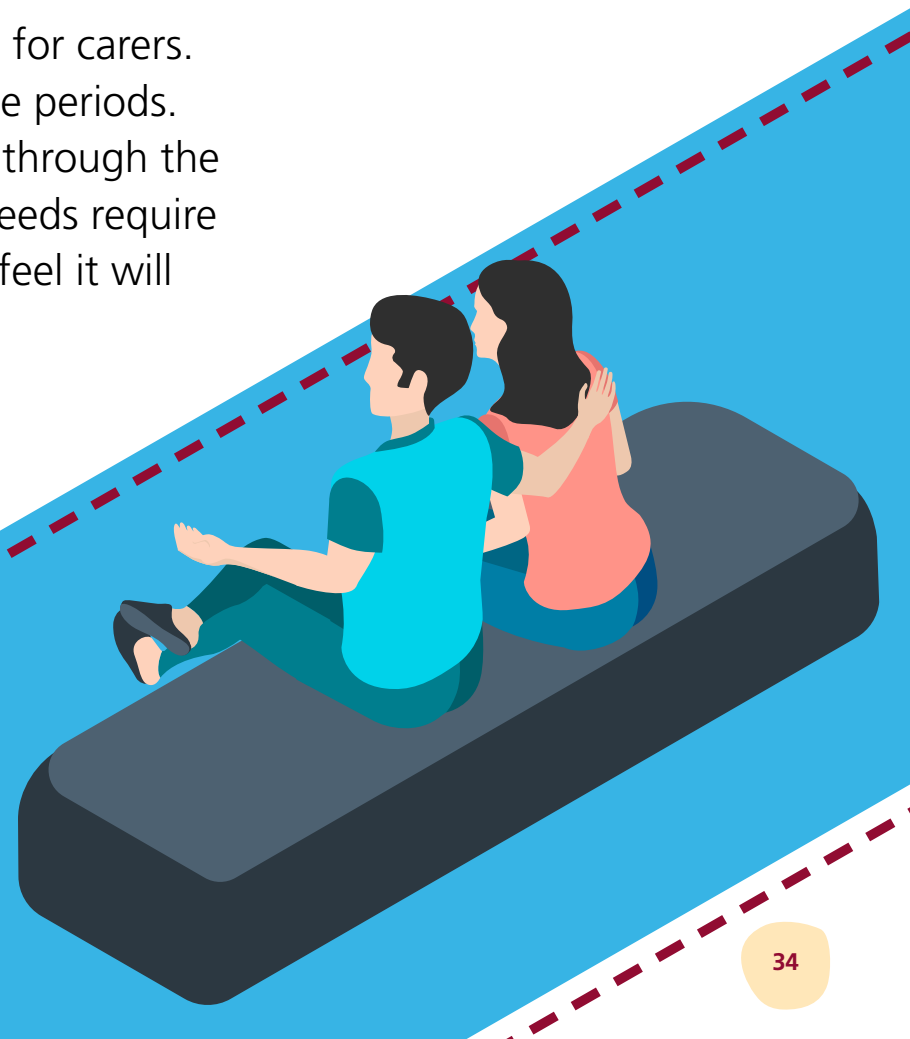
Transition between different levels of security

The transition between different levels of secure care can be stressful for carers. It is important for services to involve and support carers through these periods. This can be a positive, hopeful time when there is welcome progress through the system to less restrictive levels of security. Where the person's care needs require a higher level of security, it may be a worrying time for carers if they feel it will not help and progress is not happening.

Whichever it is, uncertainty about new and unfamiliar destination units, services, or even a change of ward, can add to anxiety.

What carers should expect: support and involvement in transition between different levels of security and settings of secure care

1) Carers should be involved as early as possible in assessments and planning and their views should be taken into account when making decisions around transition. They should expect to know where, when and how the transition will take place.

2) Information and advice is provided about the process, timescales and arrangements to alleviate uncertainties for carers.

3) Carers should be given information about the unit their loved one is moving to and the opportunity to visit, as well as information about things like transportation, timings and arrangements for early visits.

4) Carers should be linked to the carers' lead in the new unit.

Links to key resources

Centre for Mental Health - information about pathways into, between and out of secure care services and a report on improving these transitions. This web document briefly describes important issues that are relevant to practice and commissioning to ensure smooth and timely transitions through the pathway. There is a link to a larger more in-depth report which provides further information.

NICE Guideline: Transition between inpatient mental health settings and community or care home settings. Provides general information but is relevant to transition in secure mental health service context.

Preparation for discharge

Preparing for discharge, in particular the major transition out of secure environments, can provoke mixed feelings for carers and is usually a very stressful time. Carers can fear that they will be expected to take on additional responsibilities as their loved ones move from fairly intensively staffed units to an uncertain level of community support. Alternatively, they might feel that they want to be more involved than they are. Individual circumstances need to be taken into account and the wishes and views of carers should be taken into consideration.

Careful use of provisions to grant leave of absence for service users can assist in smoothing transitions between different levels of secure care and in successfully organising discharge from secure services. By having time away from the services people can start to adapt to being back home or to a move into a different type of service. Types of leave can include escorted and unescorted leave, leave within the grounds of a hospital, or out into the community. The latter can involve overnight trips to the family home. Ideally, carers will be involved in planning decisions and evaluating periods of leave.

Co-produced assessment and management of risks and needs can be a great help in supporting both service users and carers. It can also help in avoiding returns to secure hospital care. If the service user is being discharged and the relative is going to be a formal carer, then there should be a proper Care Act (2014) assessment as part of the discharge planning.

Conditional discharge, aftercare and Community Treatment Orders
Various circumstances allow for discharge from hospital with conditions attached. After-care is the term used in the Mental Health Act for entitlements to care and support following discharge from hospital. Both Mental Health Tribunals and the HM Prison and Probation Service Mental Health Casework Section can grant a Conditional Discharge for restricted patients. Conditions might include:
• Stipulated place of residence
• Co-operation with community services, compliance with treatment and supervision by Responsible Clinician (RC)
• Abstinence from drugs and alcohol
• Drug screening
• Exclusion zones
• Restricted contact with families.

Community Treatment Orders (CTOs) have been possible since the 2007 reform of the Mental Health Act (1983). These also allow for conditions on remaining in the community, which are defined by the RC, such as where medication must be taken. For both Conditional Discharge and CTOs a person subject to these provisions can be brought back into hospital if a breach of conditions is associated with a combination of risk to the public and mental disorder.

Discharge arrangements for high-risk service users

Service users assessed as posing a high-risk on discharge will be subject to continuing restrictions and supervision in the community. The Multi-Agency Public Protection Arrangements (MAPPA) are in place for this purpose. They involve processes by which the police, probation, and health services work together with other agencies to coordinate input and effectively supervise and monitor progress in the community to maintain safety. The MAPPA process ensures sharing of information and accountability of agencies. Multi-Agency Risk Assessment Conferences (MARAC) are the similar process for managing the safety of victims of high risk domestic abuse.

In circumstances were the service user is deemed to be vulnerable then provisions for safeguarding adults will apply, obliging Clinical Commissioning Groups (CCGs) and local authority social services to provide appropriate services and support. The Local Authority leads on Safeguarding Adults.

Supporting carers who have been victimised

The Mental Health Casework Section of Her Majesty's Prison and Probation Service (HMPPS) has responsibility for restricted patients under the Mental Health Act (1983) on discharge from a hospital.

There are specific provisions for the victims of service users, who may include family members where the offence has been committed within the family. A Victim Liaison Officer (VLO) supports this process, including supporting the carers to make representations to the Mental Health Tribunal or the Ministry of Justice about the conditions of a service user's discharge, and liaison within the MAPPA process. Hospital managers have similar responsibilities regarding the victims of non–restricted patients.

What carers should expect: support and involvement in discharge and preparation for discharge

1) Carers views are sought about their feelings and they are given advice about their loved one being discharged. Issues should be noted and action taken in response where possible.

2) Services should invite carers to be involved in pre-discharge care planning and risk management processes and support them to be involved. This should include putting a plan in place that can be used if carers have concerns or if things begin to deteriorate in the period after discharge. After discharge, carers will not be able to attend MAPPA/MARAC meetings. But they should be able to contribute their views and have their perspectives taken into account.

3) Carers should have a continued point of contact agreed prior to discharge, including where service users are moved out of their home area, to ensure they can seek advice and continue to provide insight and information to services.

38

Links to key resources

NICE Guideline: Transition between inpatient mental health settings and community or care home settings. Provides general information but relevant to transition in a secure mental health service context.

Information and guidance about leave provisions: Leave is granted under Section 17 of the Mental Health Act. There is specific guidance for such leave in the secure care context provided by the National Offender Management Service Mental Health Casework Section. The work of the National Offender Management Service is now undertaken by Her Majesty's Prison and Probation Service (HMPPS).

Royal College of Psychiatrists Standards for Community Forensic Mental Health Services. These quality standards define expectations of community forensic mental health teams and address carer needs and involvement.

Stepping out: the needs of women discharged from secure mental health services. This research report focuses on meeting the needs of women discharged from secure services. There is an emphasis upon actual services and imagining ideal services as they might be.

The Mental Health Law Online website has useful general information about mental health law and links to other websites. Specific information about Conditional Discharge can be found on the site.

The Rethink Mental Illness charity has plenty of useful information about mental health care, including particular information about CTOs: (Community Treatment Orders).

MAPPA website: Multi-Agency Public Protection Arrangements. These arrangements apply to individuals deemed to be high-risk on discharge from secure mental health care or prison.

Her Majesty's Prison and Probation Service Mental Health Case Work Section: Working with Restricted Patients and Stakeholder Engagement Framework. These documents outline the remit of the Mental Health Case Work Section, their responsibilities for restricted patients after discharge from hospital, and vision and values.

The Social Care Institute for Excellence (SCIE) has a web-based guide to the Social Care Act (2014). Within this is specific guidance, a checklist and resources regarding Safeguarding Adults Boards.

Carer involvement in service planning and design

Carers like myself have a lot to offer services, helping them to do better. Recently there have been more opportunities to get involved and make a difference. But we don't always have the chance for this. A network for carers would be very welcome.

Carer

Forensic carers have a valuable contribution to make to strategic planning within and between services. The [Five Year Forward View for Mental Health](#) (2016) urged that "Services must be designed in partnership with people who have mental health problems and their carers" and commissioners will "co-produce with clinicians, experts by experience and carers".

Carers associated with certain units are involved in the [Royal College of Psychiatrists Quality Network for Forensic Mental Health](#), which audits services against agreed standards (including a standard for carer involvement) and shares best practice ideas. This ensures that carers play an active role in the development and improvement initiatives.

A commitment to involving carers in service development is important. As part of this commitment, it is important to recognise that to effectively engage with some groups of carers, additional steps may need to be taken. For example, where English is not a carer's first language, or where a carer may have a sight or hearing impairment, practical steps may need to be taken to facilitate communication and participation. Less obvious may be the needs of carers from LGBT communities or older carers. What matters, is a willingness to take proactive but reasonable steps to facilitate meaningful engagement with all groups of carers.

Many carers have suggested that a network, similar in approach to the [Recovery and Outcomes Network](#) model, would be valuable for carers. The purpose of such a network would be to share good practice, receive national information, and streamline carer involvement. This would help carers to feel less isolated, share experiences, and develop their expertise. Moreover, the network could assist development of peer carer support, co-production of information, and influence service improvement.

What carers should expect: support and involvement in service planning and design

1) Services should consider the development of service development groups for carers (strategic forums). These would be separate to carers groups and focus on service development.

2) Services should seek to address equality issues in services by engaging with carers with direct experience of those issues.

3) The development of a network modelled on the Recovery and Outcomes Network should be explored.

4) Co-production of information leaflets/activities/strategies/processes etc. This could include involvement in planning carer days, running support groups, planning conferences, planning courses in recovery colleges, developing information, sitting on key groups within services, attending Recovery and Outcomes groups, joint planning meetings with service users, and involvement in training.

Practice examples

Within the toolkit we include some of the many examples that were identified by carers and providers, to highlight different ways of working with carers in secure settings. We hope by highlighting some of these examples we will encourage interested people to make contact and learn from each other, enabling further work in this area.

Mersey Care NHS Foundation Trust development of Seclusion and Segregation Policy. This Trust-wide Policy and Procedure for the use of Seclusion and Long Term Segregation is notable for the involvement of service users and carers in its development. The Trust has a mixture of high, medium and low secure services. The carers involved in the process appreciated the efforts made to genuinely seek their views and act upon them. This led to authentic and meaningful experiences of involvement. This work shows how the way policies are written can change the culture of organisations and further empower carers.This policy, although lengthy, is written in plain English and is accessible to carers. It tells staff the responsibilities they have to carers if their relative is in seclusion and gives carers a clear understanding of the way their relative should be treated when in seclusion.

Contact person:
Amanda McBride - Senior Forensic Social Worker/Carer Lead
[I/S]

Cygnet Hospitals People's Council
Cygnet Hospitals have developed a networked People's Council that comprises democratic meetings organised at unit, regional and national levels. These forums include carers, service users and staff. The national People's Council has Board representation and seeks to influence strategic development at all levels. The People's Council aims to involve people in a collaborative dialogue that makes for safer, happier services. The People's Council involves carers who are both internal and external to the organisation as well as Experts by Experience who are carers. The People's Council also involved former and current service users, external Experts by Experience, staff, stakeholders (such as Care Quality Commission (CQC)) and third sector organisations.

Thus, meetings are supported by people who have previously used the service, peer workers and staff in dedicated roles and a lead and deputy service user from each ward, selected by application and interview. The overarching aims are:

• To ensure voices are heard at all levels of the organisation.
• Make positive changes to services, now and in the future.
• Influence practice and procedures across the different hospitals in the organisation.

The different levels of meetings gather feedback and channel this upwards, to the Board. There is an ethos of sharing best practice across hospitals, co-producing policies and procedures, challenging and supporting the organisation to do better, thinking up innovative projects and ideas, and reviewing complaints to develop solutions.

Contact
Rafik Hamaizia - Expert by Experience Lead
[I/S]

Tees, Esk and Wear Valleys (TEWV) – NHS Foundation Trust – SDG (service development group) is a monthly strategic meeting with carers, service users and staff from all disciplines. This forensic SDG is one of five within the Trust, covering all five major specialties, and chaired by a senior clinical director. The SDG has a number of roles:

- To develop standards of practice and ensure services are informed by learning from experience, feedback, outcomes data, benchmarking, research etc.
- To review national policies/strategies and identify their implications for TEWV.
- To lead the implementation strategy of NICE guidelines.
- To commission reviews of areas of practice, service user experience, clinical safety and effectiveness, service development, improvement and governance as indicated by local, regional or national drivers.
- To lead the development and implementation of the annual Clinical Audit Programme for the specialty.
- To promote the adoption and use of the TEWV Quality Improvement methodology.
- To provide a forum that brings together clinical leaders with common interests to share experiences – accelerating and enabling widespread learning from that experience to improve the quality and value of what it does.
- To promote a positive culture in the specialty of person-centred, compassionate care that helps individuals gain control of their lives to lead a healthy lifestyle of their choosing – incorporating positive risk taking, harm minimisation, health and wellbeing.

• To promote appreciative enquiry, research and development supporting specialty-wide, agreed research programmes and proposing new programmes for consideration by the Trust's Research and Development Group.

The work of the group enables carers to understand the processes that go on in the unit to improve the service. The SDG members receive thematic reviews for discussion each month e.g. restrictive interventions and practice, recovery and outcome workstream, therapeutic interventions and physical health. Professionals don't shy away from difficult conversations; they are honest and straightforward thus enabling the service users and carers attending to trust the service. The SDG is seen to make a tangible difference to the service.

Contact person:
Dr Ahmad Khouja
Deputy Medical Director
[I/S]

Cheswold Park Hospital, Riverside Healthcare. Regular carers' meetings have addressed strategic issues in the hospital since 2016. The agenda has been driven by carers, and there has been carer involvement in the development of:

• A re-written handbook and carers' survey.
• New information files for the reception and visitors' rooms.
• Refurbishment and redecoration of the visitors' room.
• Friends and family liaison leads for each ward.
• An information display screen in reception showing secure areas of the hospital that loved ones use.
• Initiatives to reduce restrictive practices.
• Providing service users with access to mobile phones.
• Meeting CQUIN targets.

Contact person:
Kathryn Crossley - Social Work Clinical Team Leader
[I/S]

Greater Manchester Mental Health NHS Trust. This Trust has invested in an impressive and wide ranging scope of strategic initiatives that support service user and carer involvement. Service users, carers and staff have worked together to develop a comprehensive and forward looking Carers' Strategy and a Carers' Charter. They cover all of the Trust's services, including, but not exclusively secure care.

The Trust's adult forensic service launched a 'Get Active, Get Involved' campaign, which encourages people to get involved with its work by participating in service meetings, helping to recruit new staff or supporting the development and delivery of staff training. This is a way in which service users and their carers can shape how services develop. Innovative approaches to gather feedback have included using an electronic 'kiosk' located in the reception area at the Edenfield Centre in Prestwich, which enabled people to participate in an 'onscreen' survey.

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Links to key resources

Royal College of Psychiatrists Quality Network for Forensic Mental Health Services. This quality network is organised by the Royal College of Psychiatrists but is open to all staff in secure units, and service users and carers can get involved, usually through their home service. The network has separate sections for Low Secure Units (LSUs) and Medium Secure Units (MSUs), and audits services against agreed quality standards. Within the network, there is a growing interest in improving the support and involvement of carers, and key standards address this.

Recovery and Outcomes Network: This national network is arranged across nine geographical areas, is managed by Rethink Mental Illness, and coordinated by an ex-service user of secure services. The network brings together staff and service users from different providers to develop strategic thinking and share best practice. Carers' issues have been considered by the network, and the network itself could be a model for similar national networks for carers.

Annex 1: Legal and policy context

- Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England is NHS England's statutory guidance about how the public should be involved in commissioning. This guidance is founded upon duties to support involvement enshrined in Section 13Q (duties for NHS England) and Section 14Z(2) (duties for Clinical Commissioning Groups) of the Health and Social Care Act (2012).

- NICE Guidelines around the provision of support for adult carers are currently under development as 'Carers: provision of support for adult carers'.

- The Mental Health Act Code of Practice (CoP) includes an empowerment and involvement principle that when appropriate the views of families and other carers should be fully considered when taking decisions. To enable this the CoP urges services to encourage service users to agree to carer involvement and provide support and information for carers. The CoP also deals with issues of confidentiality, the role of nearest relative and involvement in tribunals.

- Revised service specifications have been produced for all medium and low secure units in England. These specifications have been developed with forensic carer involvement and will in the future link directly to this toolkit.

- The Triangle of Care provides a clear framework for how the general needs of carers should be addressed, including:
  - Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
  - Staff in secure services are 'carer aware' and trained in carer engagement strategies.
  - Policy and practice protocols regarding confidentiality and sharing information are in place.
  - Defined post(s) responsible for carers is/are in place.
  - A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
  - A range of carer support services is available.

The Triangle of Care was developed by the Carers Trust who also provide a wealth of other information for carers.

- The Care Act 2014 identifies carers as key partners in providing care along with health and social care service providers and local authorities. It also places a duty on local authorities to assess carers' current and future needs for support.
- Centre for Mental Health report. Supporting carers: Mental health carers' assessments in policy and practice.

- The Five Year Forward View for Mental Health includes information about how carers should be involved in both planning and commissioning and how human rights, including the right to maintain family life are to be respected. This ought to include service users being involved in decisions about how information is shared with important others, including family members. The document includes reference to a workforce strategy to include attention to staff understanding of carer involvement. There is also intent to strengthen CQC regulation and inspection in terms of the complexity of issues of confidentiality in sharing information with carers.

- Social circumstances report for tribunals: Under the Tribunals, Courts and Enforcement Act 2007 in England there is a regulatory requirement for a social circumstances report (SCR) to be provided to mental health tribunals. The SCR should provide details of any planned aftercare in line with the guidance of the CoP and relevant CPA Guidance. Carers can also write in independently to the tribunal.

- The Care Programme Approach (CPA) Guidance sets out how all service users under the care of secure services will be dealt with under the enhanced CPA provisions. This provides for entitlements to: a CPA care coordinator, a comprehensive multi-disciplinary, multi-agency assessment of needs and risks, a similarly comprehensive written care plan including attention to matters of risk and safety and contingency or crisis plans, regular review at least once a year involving all disciplines and agencies, and rights to advocacy. Importantly, this should involve making sure any carers are identified and informed of their rights to their own assessment.

- Carers of young people or adults with learning disabilities who exhibit challenging behaviour may also have the opportunity to take part in specific review processes. These are called Care and Treatment Reviews (adults) and Care, Education, and Treatment Reviews (children and young people).

- The 2005 Code of Practice for Victims of Crime outlines the minimum standards victims can expect to receive from a number of criminal justice agencies.

- Section 117 of the Mental Health Act provides for aftercare arrangements on discharge from hospital.

- The Lammy Review
  The Lammy Review, chaired by David Lammy MP, was an independent review of the treatment of, and outcomes for, Black, Asian and Minority Ethnic (BAME) individuals in the Criminal Justice System (CJS). Details can be [located here](#). The final report called for action on a number of fronts, including in relation to mental health and detention.

- Equality and Human Rights Commission (EHRC) - Healing a divided Britain: the need for a comprehensive race equality strategy
  The EHRC published Healing a divided Britain: the need for a [comprehensive race equality strategy](#) in 2016. The report provides a comprehensive analysis on whether our society lives up to its promise to be fair to all its citizens. It looks across every area of people's lives and has specific chapters on mental health, the criminal justice system and detention.

- The Race Disparity Audit (RDA)
  The Government's [Race Disparity Audit Report](#), published in October 2017, identifies racial disparities and inequalities in public services in criminal justice and health. Alongside this report, the [Ethnicity Facts and Figures](#) website provides data on these racial disparities. Important racial disparities have been identified in relation to Crime, Justice and the Law and Health; the Audit identifies important racial disparities in mental health in the aforementioned areas. The Audit and the associated web resource confirm the existence of longstanding racial disparities that disadvantage people from BAME communities that are relevant to working with service users and carers.

- A roadmap to race equality – EHRC October 2017
  [A roadmap to race equality](#) was published in response to the Race Disparity Audit and sets out recommendations for government on tackling race inequality in Britain. It includes five priority areas for action: health; education; employment; criminal justice; and housing. The three key priorities are set out below.

Take action to close health inequalities experienced by ethnic minorities. This should include improving access to information about available services, providing these in different languages and formats; collecting data on access, experience and outcomes from health service users; ensuring healthcare professionals understand the different needs of diverse communities; and trialling interventions to assess what works in improving the healthcare experience for ethnic minorities.

Appoint an Equalities Champion with responsibility for tackling race inequality, particularly in relation to mental health, as recommended by the Mental Health Taskforce.

Improve the quality of data collection and analysis on the access, outcomes and experiences of patients in mental health settings in order to better address the disproportionalities for Black people and to identify early strategies and care pathways that are appropriate to the mental health needs of ethnic minority communities.

Annex 2: Glossary

Advocacy: An advocate supports a service user to represent their views and ensure they are heard. Advocacy also helps service users to access information from services and secure their rights under mental health legislation, including the rights of the nearest relative. Any person subject to compulsion under the Mental Health Act has a legal right to an Independent Mental Health Advocate. Similarly, in the context of people who lack capacity, there are Independent Mental Capacity Advocates.

Carer: An individual who provides or intends to provide practical and emotional support to someone with a mental health problem. They may or may not live with the person cared for. In the context of this toolkit we use the term carer to include family members and friends.

Care Programme Approach: This is the routine system for coordinating and organising the care of service users. It is led by a care coordinator, who can be anybody in a professional care role. There are regular meetings, most usually six monthly, to which relevant people, including carers, are invited.

Care and Treatment Reviews: These reviews are part of NHS England's commitment to transforming services for people with learning disabilities, autism or both. CTRs are for people whose behaviour is seen as challenging and/or for people with a mental health condition.

The reviews aim to ensure people are receiving the most appropriate care and treatment at the least restrictive level. These reviews involve multiple stakeholders as in CPA meetings, including carers. They have been credited with reducing numbers of people in this group being cared for in hospital. Care, Education and Treatment Reviews are a similar process for young people.

Commissioning: Commissioning is the way in which health services are organised and paid for. It involves one set of NHS organisations (commissioning bodies such as CCGs) making contracts with provider organisations, such as hospitals, to provide the service. The commissioning process involves planning and reviewing performance and is also a focus for service user and carer involvement. Secure mental health services are commissioned by NHS England; the specialised commissioners are organised across four regional teams. Staff responsible for the commissioning process are called commissioners. Mental Health Case Managers are part of the commissioning team.

CQUIN: This stands for commissioning for quality and innovation. The CQUIN system was introduced in 2009 to make a proportion of healthcare providers' payment conditional on demonstrating improvements in quality and innovation in specified areas of care.

Forensic mental health care: The word 'forensic' means related to the law or the legal system. In the mental health context, it is used to indicate services that care for individuals who have arrived at mental health services via the criminal justice system: police, courts, prison. In this toolkit we use the term secure mental health services or secure care to include forensic mental health care.

Forensic carer: Someone of any age who provides unpaid support for a relative or friend who is using forensic mental health services, including those provided in low, medium and high secure and community settings.

Protected characteristics: Protected characteristics are personal characteristics protected under the Equality Act 2010. Under this legislation, the term 'protected' means that it is unlawful to discriminate against, harass or victimise people who have that characteristic. There are nine characteristics protected: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; and sexual orientation. The Equality and Human Rights Commission (EHRC) provides a lay person's definition of each term on its website.

Providers: Organisations or services that provide care – in this context, usually meaning secure hospitals or units. You may also see 'service providers' and 'service provider staff', the latter referring to the healthcare personnel who work in provider services.

Psychosocial interventions: A range of therapies that can be offered as part of care and treatment. They are 'psycho' because they are psychologically informed and 'social' because they attempt to involve carers directly or at least take account of social issues. The most obvious examples are forms of family therapy, where a number of family members meet with a therapist and learn different ways of talking and relating to each other, which help them to cope with mental health difficulties and other stress.

Race and ethnicity: Under the Equality Act 2010, race refers to a group of people defined by their race, colour or nationality (including citizenship) or ethnic or national origins. This is important because people from BAME

communities are overrepresented in a number of areas of mental health practice including sectioning and other forms of detention under relevant mental health legislation.

Secure mental health services: Adult secure services provide care and treatment for men and women with mental and/or neurodevelopment disorders who are liable to be detained under the Mental Health Act (MHA) 1983, and whose risk of harm to others and risk of escape from hospital cannot be managed safely within other mental health settings. These disorders include mental illness (MI), personality disorder (PD) and neurodevelopmental disorders (NDD), including learning disabilities (LD) and autistic spectrum disorders (ASD).

Service users will typically have complex chronic mental disorders, which are linked to offending or seriously harmful behaviour, some will be involved with the criminal justice system (CJS), courts and prison, and may have Ministry of Justice (MoJ) restrictions imposed. These services operate across a number of levels of security to manage different levels of risk to others, each of which provides a range of physical, procedural and relational security measures to ensure effective treatment and care whilst providing for the safety of the individual and others including other service users, staff and the general public.

- Low secure services care for those who provide a significant risk of harm to others and whose escape from hospital should be impeded.
- Medium secure services care for those who present a serious risk of harm to others and whose escape from hospital should be prevented.
- High secure services care for those who present a grave and immediate danger to the public and who should not be able to escape from hospital.

Secure services provide a comprehensive range of evidence-based care and treatment provided by practitioners, who are expert in the field of forensic mental health. A range of specialist treatment programmes is available, delivered either individually or within groups. The aim is always for the individual to either, safely return to the community, to a lower level of security, to prison or transfer out of secure services.

Service user: A person receiving health or social care services. Here, the term usually refers to someone who is using secure mental health services. Some people prefer the terms 'client', 'patient' or 'consumer'. The terminology of service user has been taken up within various participation and involvement practices, hence the term service user involvement.

Social circumstances report: These reports are drawn up to be presented to tribunals. They are mandatory in England for all but Section 2 cases. The report should describe any planned aftercare following appropriate guidance. Carers can also independently submit their views to the tribunal. The main purpose of an SCR is to inform the tribunal of a person's likely circumstances if discharged from hospital. This should include reference to the availability of health, social services or other support. The views of carers must also be taken into account, as well as assessment of a service user's strengths and capabilities.

Triangle of Care: A key guide to best practice in the support and involvement of carers produced by the Carers Trust. Available as a booklet, the guide presents six standards for achieving better collaboration and partnership with carers. It offers best practice examples and links to resources, and an audit process for evaluating success. The overall, simple idea is that the three-way partnership between carers, service users and service providers will produce best outcomes.

Tribunal: Short for Mental Health Act Tribunal. These are independent panels for appealing against sectioning under the MHA. They can discharge people from their sections, grant leave, order hospital transfers, recommend supervised community treatment as an alternative to hospital, decide upon delayed discharge or conditional discharge. Hospitals are not necessarily bound by tribunal recommendations, but the tribunal can reconvene if recommendations are not acted upon.

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The team involved researchers who undertook a literature review and original research to inform the toolkit and a steering group who oversaw the project. All were involved in the writing and review of the toolkit.

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The films included in this toolkit were produced by **Sybil Ah-Mane** and **Russell Hall** at Flexible Films. Flexible Films specialise in making co-productive films in health and social care.