



Framework for patient and public participation in Health and Justice commissioning

OFFICIAL

NHS England INFORMATION READER BOX

Directorate

Medical	Operations and Information	Specialised Commissioning
Nursing	Trans. & Corp. Ops.	Commissioning Strategy
Finance		

Publications Gateway Reference: 06312

Document Purpose	Guidance
Document Name	Framework for Patient and Public Participation in Health and Justice Commissioning
Author	NHS England/Public Participation Team
Publication Date	January 2017
Target Audience	NHS England Regional Directors, NHS England Directors of Commissioning Operations
Additional Circulation List	CCG Clinical Leaders, Partner organisations, voluntary and community sector partners, patient groups, NHS England Regional Directors, NHS England Directors of Commissioning Operations, All NHS England
Description	Framework to strengthen patient and public participation in health and justice commissioning.
Cross Reference	Patient and Public Participation Policy, Statement of Arrangement on Patient and Public Participaton in Commissioning
Superseded Docs (if applicable)	N/a
Action Required	For implementation
Timing / Deadlines (if applicable)	N/a
Contact Details for further information	Public Participation Team NHS England Quarry House, Leeds LS2 7UE 0113 8250861 england.nhs.participation@nhs.net

Document Status

This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto local or network drives but should always be accessed from the intranet.

Framework for patient and public participation in Health and Justice commissioning

Version number: 1

First published: January 2017

Prepared by: Public Engagement Lead, Public Participation Team

This is a controlled document. Whilst this document may be printed, the electronic version posted on the NHS England website and intranet is the controlled copy. Any printed copies of the document are not controlled.

As a controlled document, this document should not be saved onto local or networks drives but should always be accessed from the NHS England website or intranet.

Other formats of this document are available on request. Please send your request to england.nhs.participation@nhs.net

SUMMARY OF KEY POINTS AND ACTIONS FOR HEALTH AND JUSTICE COMMISSIONERS

- Patient and public participation is an essential component of commissioning, and should be considered at all stages of the commissioning cycle (planning, buying and monitoring health and care services).
- Consider the need for – and best approach to – participation depending on the situation, the population in question, and existing sources of information and insight; these sources may be national, regional or local.
- People using health and justice services may face specific barriers to engagement. Involve people in ways that are appropriate to their needs and preferences, and provide them with the necessary information, resources and support to enable them to participate.
- Work with partners to involve people, including other commissioners, providers, service user and carer networks, Healthwatch, and the voluntary and community sector.
- Plan for participation – including identifying benefits (with measures of impact where appropriate) and costing participation activity; participation plans need to be factored in to overall business planning and programme planning.
- Involve people early on in the process, not as an afterthought.
- Feed back to those you have involved about the impact of their participation. Explain how their participation has influenced commissioning, and if not, why not.
- Keep good records of your approach to participation including how you have assessed the legal duty to involve the public in commissioning. **NHS England commissioners are required to document their assessment of whether Section 13Q (the legal duty to involve the public in commissioning) applies using the [standard form available on the NHS England intranet](#).**
- Document and report on participation activities and **impact**, for assurance and quality improvement purposes, publicising and celebrating success and sharing learning.
- NHS England needs to work in partnership with other commissioners and providers to make health and justice services joined up and effective for service users.

Contents

Contents	5
1. Introduction.....	8
2. Context.....	10
2.1 What health and justice settings and programmes are covered by this framework?	10
2.2 Who are our patient and public stakeholders in health and justice commissioning?	12
3. Core principles for patient and public participation in health and justice services. 13	
3.1 Experience	13
3.2 Diversity	13
3.3 Equity	14
3.4 Transparency	15
3.5 Governance and assurance	15
3.6 Outcomes and feedback	15
4. Embedding patient and public participation in the commissioning cycle.....	16
4.1 Barriers to participation	18
5. Governance arrangements for patient and public participation.....	21
5.1 National arrangements.....	21
5.2 Regional arrangements.....	21
Appendix: Resources to support participation	23
A. Participation in the Commissioning Cycle.....	23
B. Patient and public networks and sources of insight.....	26
C. NHS England guidance and advice	28
D. Engagement approaches for different health and justice settings and communities.....	29
D1. People detained in prisons.....	29
D2. Children and Young People in Young Offenders Institutes, Secure Training Centres and Secure Children’s Homes	32
D3. Service users of Liaison and Diversion Schemes	35
D4. Service users from black, Asian and minority ethnic communities.....	37
D5. Older offenders	39
D6. Victims and survivors of rape and sexual assault (users of Sexual Assault Referral Centres).....	40
D7. Adult survivors of childhood sexual abuse, rape and sexual assault	43
D8. Children and young people who are victims and survivors of rape and sexual abuse.....	47
D9. Service users in Immigration Removal Centres	52
D10. Involving families and carers.....	55
D11. Service users in Mother and Baby Units	58
E Involving people in procurement.....	59
F Involving patients and the public in quality assurance	62
G Useful lines of enquiry to follow up with providers	63
Glossary and Additional Resources.....	64

Acknowledgements 65

OFFICIAL

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

1. Introduction

NHS England wants to involve patients and the public in health and justice commissioning to design and deliver effective services that meet the needs of people in contact with these services.

This framework is a guide for NHS commissioners of health and justice services - and anyone who is interested, including patients and the public, the voluntary sector, and providers of health and social care services. The framework describes how NHS England involves patients and the public in the commissioning of health and justice services.

In our definition of 'patient and public participation' we mean service users, patients, children and young people, carers and families and those with lived experience, as well as the wider public and stakeholder organisations representing these networks and communities.

By 'participation in commissioning' we refer to how people are involved in planning (including policy making and relevant programmes), buying and monitoring of health and justice services.

Whilst participation is an essential consideration in our work, and is not merely a 'nice to do' task, we recognise that it can take many different forms. For example, patients and the public may be involved through a formal consultation, by being sent information directly, or through face to face meetings.

This framework has been co-designed with members of a stakeholder group for Patient and Public Participation in Health and Justice Commissioning. Membership of this group includes user groups, the voluntary sector and commissioners (membership can be seen in the [acknowledgements section](#) of this framework).

The framework is designed to be read in conjunction with the NHS England [Patient and Public Participation Policy](#) and the [Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning](#).

The Patient and Public Participation Policy sets out our ambition to strengthen patient and public participation in all of our work, and how we intend to achieve this, in line with the vision for the NHS set out in the Five Year Forward View. Our policy and associated documents are based on the belief that health services and outcomes are better when people who need, use and care about services have meaningful opportunities to be involved in them.

The Statement of Arrangements is for NHS England commissioners working in all areas of direct commissioning (primary care, public health, health in justice, specialised services and services for the armed forces). It identifies where our legal duty to involve the public in commissioning under **Section 13Q of the Health and Social Care Act 2006 (as amended)** applies. It sets out guidance for commissioners on how to involve the public, including:

- Principles for fair and proportionate involvement

OFFICIAL

- When public involvement should take place
- Case studies, many of which refer to primary care commissioning.

This framework is specific to health and justice, it supports commissioners to:

- Involve service users of all ages, patients, families, carers, communities and staff in all aspects of commissioning.
- Address our legal duty to involve patients and the public in our commissioning processes and decisions.

It includes an Appendix of **practical resources** to aid commissioners in their planning and implementation of patient and public participation.

Patient and public involvement is an essential part of our work. The benefits of service user involvement are not limited to service design improvements. Involvement can have a direct benefit to service users, including improved confidence, skills and knowledge and wider wellbeing benefits. Our values are rooted in the [NHS Constitution](#), which states that the NHS belongs to us all.

2. Context

2.1 What health and justice settings and programmes are covered by this framework?

NHS England is responsible for healthcare provision in justice settings and programmes. This means that we specify, secure and monitor services to meet people's needs, sometimes in partnership with other public bodies, to make sure that the services are of a high quality and meet the need of those using the services. NHS England commissions services in the following settings and programmes:

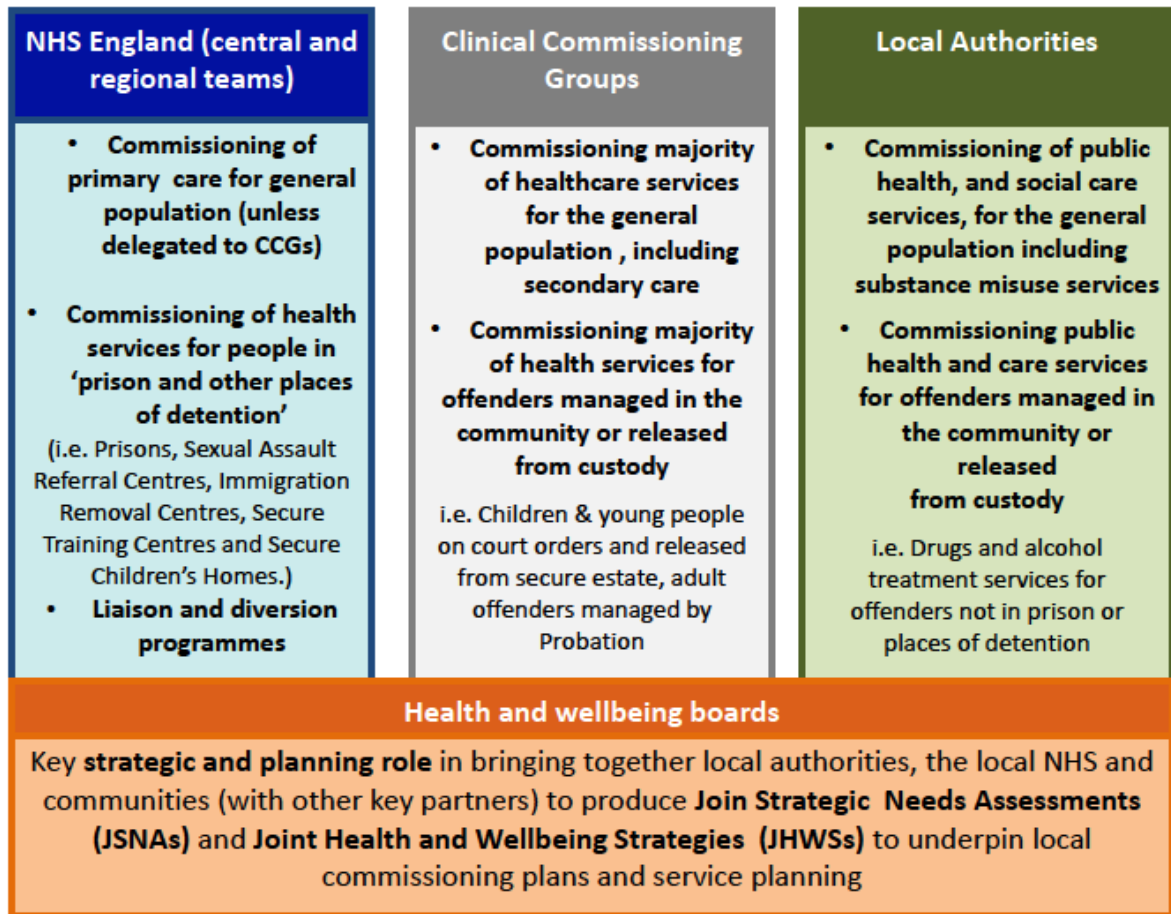
- Prisons
- Immigration Removal Centres (IRCs) and short term holding facilities (STHF)
- Sexual Assault Referral Centres (SARCs) for both adults and children and young people
- The secure estate for children and young people, including those who are detained in welfare settings
- Public health in secure and detained settings
- Liaison and diversion programmes.

We are, therefore, responsible for commissioning care for individuals at a particular point in their life which is solely defined by the setting they are in, not by their need or the nature of the service. Services are commissioned from a mixed market of providers including NHS Trusts and independent organisations.

Service user quote from an engagement workshop on this framework:

“It's been a great experience for me being involved in the Lived Experience Team for the Liaison and Diversion programme, and a few of us have moved on to working in the field, having learnt new skills and finding new levels of confidence; makes me feel good too to see that my contribution has made a change at all sorts of levels, and if that was clear to other people, then maybe they would think about getting involved.”

Figure 1 How NHS England commissioning fits into the overall commissioning of relevant services



Police and Crime Commissioners (PCCs) are responsible for local policing. They work in partnership across a range of agencies at local and national level to ensure there is a unified approach to preventing and reducing crime. They bring together community safety and criminal justice partners, to make sure local priorities are joined up.

Where joint commissioning arrangements are in place for health and justice services, then NHS England will apply the arrangements set out in the framework and guidance and other public bodies will need to make their own arrangements. Where there are interdependencies in commissioning, for example between services and pathways, or across complex conditions, commissioners should take account of patient and public insight and feedback across the pathway.

2.2 Who are our patient and public stakeholders in health and justice commissioning?

Our patient and public stakeholders include (but are not limited to):

- Those suspected of committing an offence, those convicted of offences, ex-offenders;
- Asylum seekers in Immigration removal centres (IRCs) and short term holding facilities (STHF);
- Children and young people as service users of all our health and justice services as well as children and young people who are detained for welfare reasons;
- Service users of health and justice services also include victims (of all ages) of sexual assault;
- Patients and service users;
- Carers and families;
- Stakeholder organisations (including voluntary, community and patient organisations) representing networks and communities of interest from health and justice services.

Commissioners of health services in health and justice settings should have arrangements for hearing the voices of service users of all ages as well as groups that are less often heard. It should be remembered that service users of health and justice services include victims of crime, asylum seekers and children held in secure settings on welfare grounds, as well as those who have committed criminal offences. The health inequalities of this service user population tend to be higher than those of the wider population.

Involvement activity with service users should take this into consideration and use a variety of engagement methodologies. Creative and innovative approaches can address some of the significant barriers to engagement that service users in health and justice settings might experience. Further information about insight sources and engagement approaches can be found in the appendices.

Case study

User Voice, a charity led by ex-offenders, establishes Prison Councils across the prison estate. The User Voice Prison Council model provides a democratic, structured and effective means by which elected prisoners voice collective problems and solutions. The Council provides a reference point for the design, delivery and evaluation of new and existing policies, procedures and services. The model distils the myriad of prisoner issues into general themes, rather than personal issues by using a 'party' system in an election process.

There are two sides to the User Voice Prison Council model's impact:

- Improving services – with service user insight and experience, services can become more effective and accessible for seldom heard groups.

- Promoting active citizenship – as service users engage with improving the services they access, they develop the skills and behaviours to become contributing members of society.

User Voice has used data collected through the National Offender Management Service (NOMS) Performance Hub to analyse the impact of Prison Councils in all prisons it currently operates. While it is recognised that the Prison Council does not have a direct causal link to all the indicators highlighted below, together they demonstrate an overall improvement:

- 18% fewer prison assaults
- 21% fewer prisoner on prisoner assaults
- 12.5% reduction in serious assaults on staff
- 40% reduction in the use of force
- Reduction in days lost to staff sickness
- Fewer complaints
- 13% fewer proven adjudications.

3. Core principles for patient and public participation in health and justice services

The following sections describe core principles for engagement that are particularly important when planning and implementing participation activities in the health and justice arena.

3.1 Experience

- We value the voices of service users; adults, children and young people, with recent lived experience and those who represent service users.
- Local, regional and national participation arrangements should reflect input and direct knowledge of the health and justice system.
- The role of staff in secure settings in encouraging and delivering effective participation is recognised and valued. This should be supported by appropriate staff training.
- Safeguarding considerations will be important for all service users, however it is particularly important to ensure that those engaging with children and young people have the appropriate training and disclosure and barring service (DBS) checks in place.

3.2 Diversity

- We recognise that there are differences in services across the spectrum of health and justice services, as well as a diversity of service users within each setting. These differences mean that 'one size does not fit all'; the differences need to be reflected in local arrangements to support participation and to address particular barriers experienced.
- Developing participation approaches should ensure that a diversity of service users are involved (including those who are seldom heard, and those with protected characteristics under the [Equality Act 2010](#)).

- Commissioners should undertake an Equality Impact Assessment for commissioned services. There is [guidance for NHS Commissioners on Equality and Health Inequalities Duties](#).
- Participation approaches should consider the nature of the service commissioned; for example engaging with children and young people using a service will require different approaches from engaging with adults and involving people who have experienced traumatic sexual assaults will need expert support that would differ from other engagement approaches.
- Participation should particularly include those that experience health inequalities.
- Commissioners are required to support the [Accessible Information Standard](#). This mandatory standard aims to make sure that disabled people have access to information that they can understand and any communication support they might need.
- Auditing and monitoring participation of equalities protected groups, for example in events and formal governance roles, supports commissioners to manage and improve performance in involving a more reflective range of people.
- NHS England has completed an [Equality and Health Inequalities Analysis for the NHS England Patient and Public Participation Policy and associated documents](#) which is available on our website.

3.3 Equity

- Patient and public participation opportunities should be equally available to everyone who wishes to be involved.
- Participation arrangements should seek to address the equity issues present in health and justice settings, including the addressing the barriers identified in section 4.1.
- Children and young people in the secure estate may be detained as a result of committing a criminal offence, or detained for welfare reasons. It is important to consider appropriate methodologies to enable young people to participate; often specialist support will be required. Children and young people often have multiple health, social care and educational needs.
- There are higher instances of mental ill health and learning disability within the secure estate service user communities. Service users with mental health needs or with a learning disability will often need additional support to enable their involvement.
- Activities should be planned and adapted to ensure equitable access to public participation opportunities regardless of a person's cultural, linguistic, religious background, communication and accessibility needs.
- Given that secure settings have the power to restrict service users' liberty and privileges and given the vulnerability of many service users, there are inherent power dynamics in justice settings, so issues of confidentiality and the independence (or otherwise) of the engagement work should be explained clearly to service users from the outset.
- [The Appendix](#) provides some practical tips and principles for working with different communities of people in different health and justice settings.

3.4 Transparency

- Participation approaches should use multiple sources of insight including complaints, reports, monitoring, direct listening and evidence from stakeholder organisations.
- Participation shall be practiced through transparent routes including clear governance arrangements, democratic processes or representation and engagement and transparent recruitment approaches.
- Where personal data is to be used, then assurances and details of how this will be used should be given to the participants, in line with data protection requirements, outlining:
 1. How the information will be used
 2. For what purposes
 3. Who will have access to the information (with justification if necessary)
 4. How the information will be securely stored and for how long.¹

3.5 Governance and assurance

- There should be clear governance and assurance arrangements at regional and national levels.
- Patient and public participation in health and justice commissioning should be aligned with other areas of participation within the system, for example including the activities of the Prison Service Ombudsman and Her Majesty's (HM) Inspector of Prisons. Information about participation activities and the outcomes of these should be shared between agencies where appropriate.
- Wherever possible, anonymous or pseudonymised² data should be used to report patient and public opinions. However, if identifiable information has to be used, then it should be the minimum necessary to achieve the purpose.

3.6 Outcomes and feedback

- The primary aim of engaging service users is to learn from their insight and experience in order to improve services.
- Feedback about what has happened as a result of participation should be built in to the process from the outset.
- After each programme of engagement, the outcome (what changed as a result of participation insight) should be documented. This information should be relayed to service users and others who have been involved.
- It is not always possible to act on every aspect of service user feedback. Details on what can and can't be influenced should be made clear from initial contact. It is also important to be transparent and clear in response to feedback about what actions are being taken, or not taken, and why.

¹ This is particularly important given the context, nature and sensitivity of the information involved.

² Pseudonymisation is the process of removing identifying data items from the data, leaving one strong identifier that could re-identify the person in particular circumstances (e.g.: you could remove all demographic data, and just use the NHS number. This would only make the person identifiable to those who had access to the Personal Demographics Service).

Case Study: Service user participation in West Yorkshire Adult/Paediatric Sexual Assault Referral Centre (SARC) Commissioning

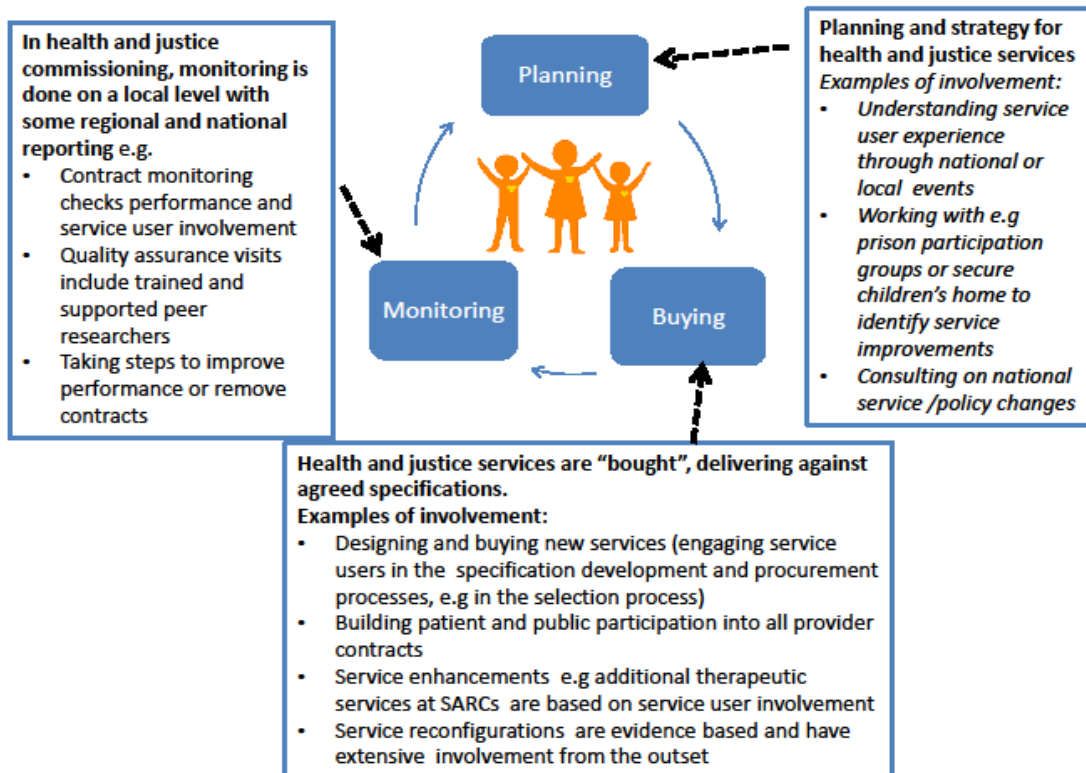
- Face to face workshops (facilitated by women's centres due to their specialist skills/knowledge) with victims and survivors to understand their opinions fed into the service specification design.
- Use of innovative technology, for example using online surveys to gather anonymous feedback.
- Specialist workers facilitated a questionnaire process on behalf of the victims and inputted their specialist views, with over 100 responses (adults and young people) received. This helped to inform the specification and Equalities Impact Assessment.
- In September 2015 – NHS England carried out a consultation exercise with staff/patients to design the interior of the newly built SARC building (and to choose its name).

4. Embedding patient and public participation in the commissioning cycle

NHS England is committed to involving patients and the public at each stage of the commissioning cycle for health and justice services. The commissioning cycle refers to the different activities that make up the process of planning and buying health services and ensuring that services are being delivered to the right quality standards and within the available financial resource. These activities may take place at a national, regional or local level.

NHS England commissioners and those working on national policy and programmes that affect how health and justice services are commissioned should consider participation as an integral part of commissioning. Participation can add value at all stages of the commissioning cycle and can happen using a range of methods. For more detail about how to engage patients and the public in different stages of the commissioning cycle, please see [section A in the Appendix](#).

Figure 2. Patient and public participation in the health and justice commissioning cycle



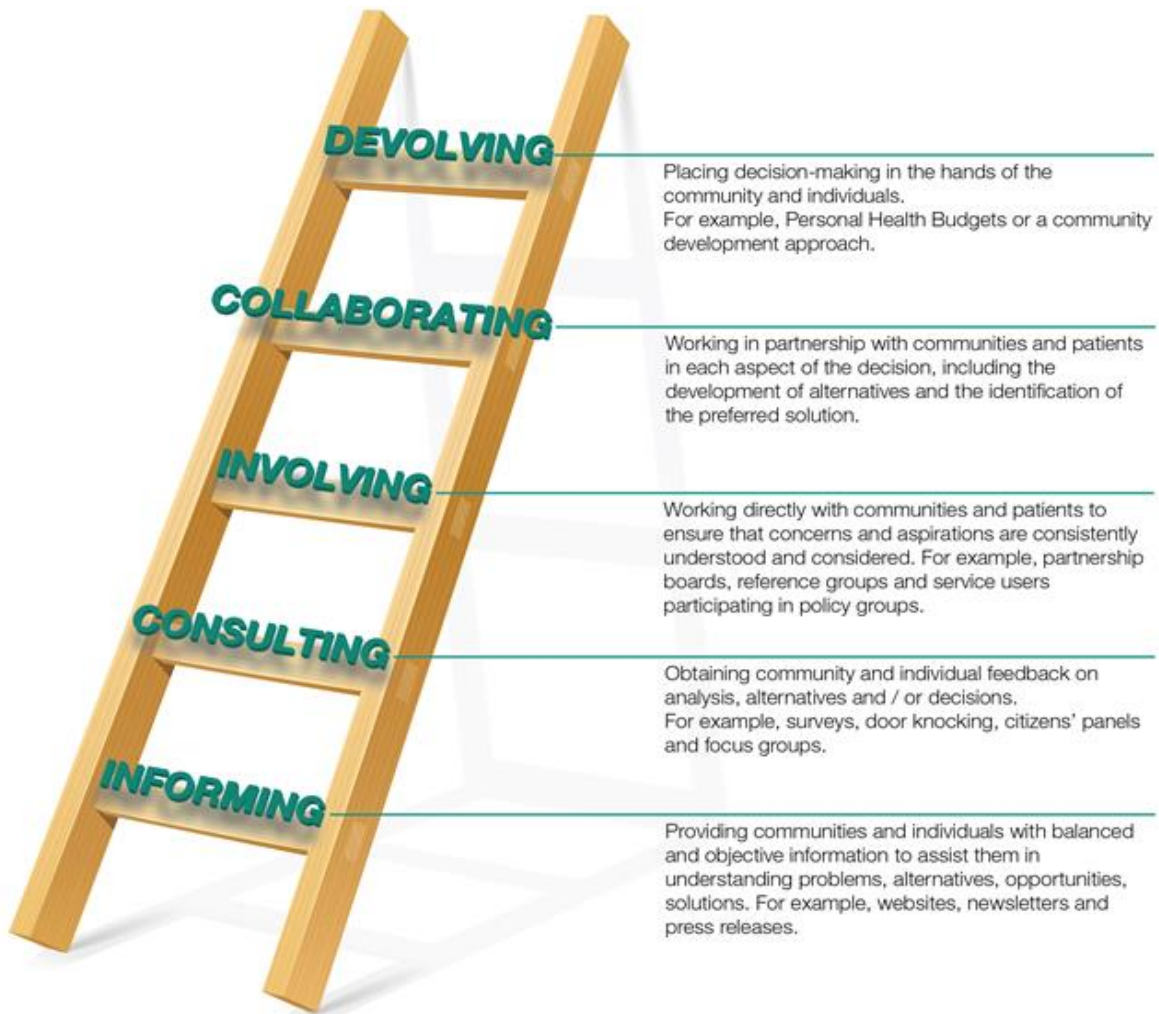
Participation should be carried out if appropriate (it may not always be necessary or beneficial), and to the extent that is appropriate to the given situation. Commissioners have significant flexibility to use a range of different participation approaches, from simply providing information through to co-production.

Different approaches will be used in different circumstances.

Figure 3. The ‘Ladder of Engagement’

This demonstrates a widely recognised model for understanding different forms of patient and public participation. It is based on the work of Sherry Arnstein³. All levels of engagement described in Arnstein’s ladder are valuable, with shared decision making approaches increasing towards the top of the ladder. All forms of patient and public participation included on the diagram below, including “informing” and “consulting”, are useful approaches to use when discharging NHS England’s duty to involve the public in commissioning.

³ [10 key ideas about participation](#)



Case Study:

West Yorkshire's Prison Procurement project (2015/16) started by developing an understanding of what insight and patient feedback already existed. The team gathered a wide range of reports and feedback from prison healthcare service users' representative groups. They also reviewed the Care Quality Commission (CQC) reports and Her Majesty's Inspectorate reports, developing a thematic analysis of key areas to address in the new commissioning round.

The themes from the report were supplemented by additional focus groups with service users, enabling the team to strengthen their understanding of the themes and to identify any gaps. Service users were subsequently trained and supported to be involved fully in the procurement assessment and appointment process.

4.1 Barriers to participation

Involving patients and the public from health and justice services has some inherent challenges that are unique to these settings and groups of individuals.

The following issues present some significant challenges that can inhibit service users from justice settings getting involved.

OFFICIAL

In health and justice commissioning, it is particularly important for NHS England commissioners to work with partners who have good knowledge of the specific service user population. The voluntary and community sector can bring valuable insight, as well as existing relationships with service users and those with lived experience.

- Service users who have experienced serious assault or trauma may need emotional support to get involved with our work. During engagement with these groups it is important to ensure that additional support is provided and to allow those who are taking part to access that support if needed.
- People in secure settings will experience barriers to digital participation and will not usually be able to attend public events without special permissions. Therefore participation approaches may need to take place within secure settings, and will need planning to account for long lead in times and security arrangements to be put in place.
- Different settings will have different security arrangements; understanding the needs of the service users and the regime within the setting will be important in order to develop appropriate and creative approaches to engagement. For example, engagement at a secure children's home may be very different from the approach used at an Immigration Removal Centre.
- Many users of justice settings are service users for a short time, including in prison, police or court custodial settings. People may be in crisis and not able to engage, or may only be using the service for a short period. They may also experience repeated short term stays in justice settings.
- There are groups who face specific barriers to participation in health and justice commissioning, and whose specific needs must be taken into account. Examples of these groups are children and young people, families, carers, patients and service users with disabilities, black, Asian and minority ethnic groups. There are also groups that experience poorer access to healthcare in secure settings and poorer health outcomes. People from underserved minority groups are often over represented in justice settings, so participation approaches should take particular care to meet their needs.
- Service users in a range of justice settings may experience language or additional communication barriers (they may have limited reading and writing skills in English, or lower overall levels of literacy). Creative visual or aural approaches can be useful.
- Asylum seekers may need additional, often specialist, support to enable their involvement.
- Health and justice service users may have had poor experiences of engagement approaches previously and participation approaches may need to develop over time to build confidence.

Assumptions, about what level or type of participation will be most effective, should be treated with caution. Where appropriate, commissioners should ask people if (and how) they would like to be involved, so that participation can be designed around their needs and preferences, and made as easy and convenient as possible for them.

Health and justice systems can be difficult to understand and navigate for patients and the public. Mechanisms to consult and engage with service users should not add to this complexity; they should be located at appropriate points on the justice pathway.

Case Study

NHS England London commissioned a user led charity, Inspirit, to develop robust and consistent user involvement practices in commissioning in establishments in the justice estate. Inspirit recruited people who have had experience of healthcare in the justice estate to collaborate with commissioners. Seven people were recruited and trained in 2015 as commissioning technicians, taking part in the development of service specifications and tender questions for providers and then marking the bids and taking part in the moderation. Based on the feedback received, the group were pleased to see that their marks ultimately affected which provider was selected. As the group developed its competencies, they developed greater autonomy. The group are now members of the Patient and Public Participation sub-group; a scrutiny panel that is working alongside commissioners to plan prison healthcare inspections. Together, with Inspirit, it is working on a set of user involvement standards to support healthcare providers to develop quality involvement activities. The group has also devised a range of work-streams with specific plans to further their work. Jen, (not her real name) said this about it;

“We choose which work-streams we want to work in. This means we get together and do something constructive, for example ... publicising our work to other ex-Prisoners. I am in two work-streams because I feel those are where my strengths lie and I have something to contribute.”

Jen is part of the recruitment work stream and has been interviewing and selecting the next group of commissioning technicians.

5. Governance arrangements for patient and public participation

5.1 National arrangements

The Health and Justice Oversight Group

This group has responsibility for national oversight of the commissioning of health and justice services by NHS England, including oversight of how patient and public participation is embedded in commissioning arrangements. The Oversight Group receives an assurance report from the regional teams at each meeting; this assurance report highlights progress and activity around service user participation. The Group is chaired by the Director for NHS Commissioning in the national team.

A new national patient and public participation advisory group

To support the implementation and development of this framework, a new Patient and Public Participation Advisory Group will be established. It will have a specific remit to identify and share innovation and good participation practice across health and justice commissioning. The group will draw on a range of service users with lived experience, stakeholder organisations and commissioners from the regional and national teams. This group will link with the Health and Justice Clinical Reference Group and will report into the Health and Justice Oversight Group (HJOG).

5.2 Regional arrangements

Regional teams commissioning health and justice services

Regional teams for Health and Justice commissioning take an overview of patient and public participation across all health and justice services within their region, setting regional priorities for action and ensuring that these are addressed. Lead Directors from each regional team provide assurance information to HJOG, as necessary. Regional teams are accountable for ensuring that appropriate patient and public participation has taken place.

Health and justice commissioning managers have responsibility for:

- Ensuring that they embed patient and public participation as an integral part of the work for which they are accountable, this includes in the planning, design, procurement, monitoring and assurance (i.e. all stages of commissioning).
- Ensuring that they are aware of NHS England's statutory duty to involve the public in this area of work, and take action as appropriate, using the processes and guidance available in the [Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning](#).
- Commissioning managers need to document their assessment of whether Section 13Q (the legal duty to involve the public in commissioning) applies using the [standard form](#) available on the NHS England intranet. This enables assessment (using guidance) of whether the legal duty to involve is triggered.

This process is summarised as:

- Forms should be completed by relevant commissioning team.
- Forms signed off and held locally by Heads of Health and Justice Commissioning.

OFFICIAL

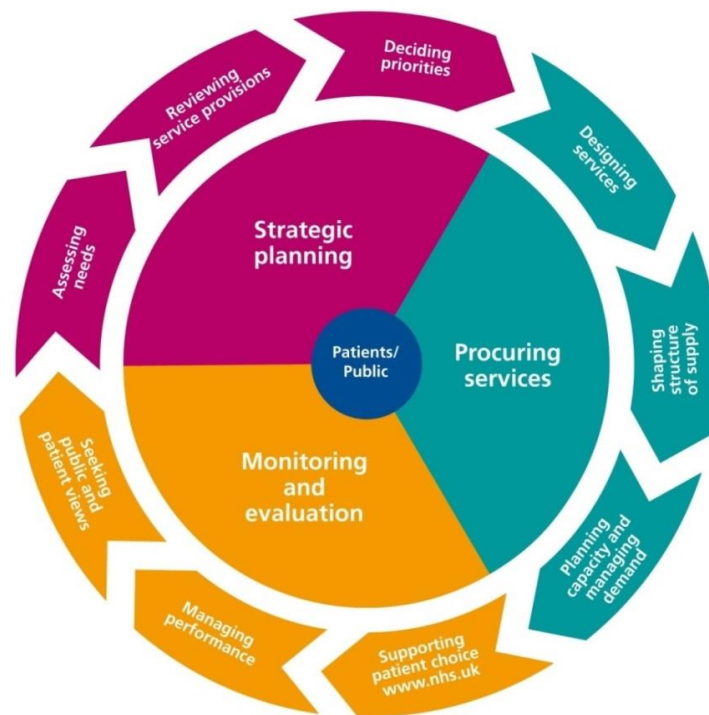
- Reporting on 13Q assessments is embedded into existing health and justice reporting and assurance processes to HJOG.
- Ensuring that the patient and public participation requirements are built into service provider contracts and are robustly monitored.
- Considering feedback generated by patient and public participation alongside other relevant data and using it to inform policy, programmes and decision-making in commissioning.
- Working consistently with the approach outlined in this framework and promoting an organisational culture in which patient and public participation is 'everyone's business'. This includes supporting formal and peer to peer learning, and celebrating success.
- Contributing to the monitoring, evaluation and reporting on implementation of this framework and the effectiveness of action to strengthen patient and public participation in commissioning.
- Document and report on participation activities and impact, for assurance and quality improvement purposes, publicising and celebrating success and sharing learning.

Appendix: Resources to support participation

This Appendix offers a series of resources to aid commissioners in their planning and implementation of patient and public participation.

A. Participation in the Commissioning Cycle

The 'Commissioning Cycle'⁴ helps to identify ways in which service users can participate in the different stages of the commissioning cycle.



At a national level:

- Use of feedback and insight data to ensure service user experience informs national planning.
- Patient and public participation (PPP) to support the development of priorities, strategies and annual plans.
- PPP to design and improve services.
- PPP involvement in procuring services.

At a regional level:

Strategic planning and service design:

- PPP is done as part of any local health needs assessments (HNA) process – as a way to triangulate data and feed into strategic planning and priority setting.

⁴ engagementcycle.org and [Transforming Participation in Health and Care 2013](#)

OFFICIAL

- PPP engagement and consultation directly influences service specification and design.
- A systematic review of already existing PPP mechanisms to understand existing patient experience, complaints and feedback.
- An Equality Impact Assessment to be carried out to ensure that any equality and diversity issues were considered when assessing and developing services for the patient group.
- Service users are involved in service reviews.
- Working in partnership with voluntary sector partners - who are experienced in involving 'experts by experience' in co-production to facilitate strategic planning of service delivery.
- Share team insight and good practice around PPP approaches; consider having this as a standing item at team meetings.
- Health and justice team try to encourage peer supported co-production. E.g. PPP workshops to be delivered by patients themselves using a peer research or peer led assurance approach.
- Involving service users with lived experience and peer research, or peer advocacy approaches have been noted to be particularly valuable approaches.

Procuring services:

- PPP workshops with local providers and stakeholders to build key service elements and the specification. A range of methods may be needed to hear from diverse service users.
- Service specifications include clear guidance for providers regarding PPP expectations.
- Create a bid evaluation project team to include service users for each procurement lot.
- Post procurement– ensuring that the service users are given feedback with a focus on outcomes of the procurement for example 'you said.... and we did....'.
- Post procurement – service user involvement in contract monitoring and assurance
- Lessons learnt sessions.

Monitoring and evaluation:

- Ensure PPP involvement in assurance processes.
- Complaints and compliments are monitored and fed into the contract management process.
- Provider progress on whether they are delivering PPP as highlighted on the bid response/local specification is reviewed at contract management meetings.
- Maintain an audit trail identifying service user input and impact.

Practical tips to feedback on involvement:

Closing the loop on engagement activity, by feeding back to service users on what has changed as a result of their feedback, is an important way of evidencing change and building accountability and credibility. This is achieved by going back to

OFFICIAL

participants with information about “You said……. So we did ……”, it might also involve explaining why some areas of feedback were not acted on; “You said …… but we haven’t done this because……”. Some suggestions for feedback are below:

- An engagement report sent to participants.
- A letter of thanks and feedback information.
- Visual, rather than written, formats can be more engaging. Consider developing an infographic, pictorial images, a poster or table or video feedback.
- A blog or newsletter update in relevant publications.
- An update meeting with direct feedback.

B. Patient and public networks and sources of insight

A key principle in making best use of patient insights in commissioning is to review and analyse existing insight sources at the start of any public involvement planning process. Where possible, use information that already exists to add value to any direct engagement approaches. Many service users and stakeholders describe being asked for the same information and insight on numerous occasions.

Service user data from within health and justice settings should also be reviewed with an understanding of who gathered the data and how. Independent service user/patient feedback is critical, where service users have been able to speak freely without fear of repercussions from providers or staff within services.

The main sources of patient insight are:

- Engagement with service user and other patient groups.
- Reports from stakeholders for example service user organisations, Healthwatch and voluntary sector groups.
- Service user and carer stories.
- Social media such as Facebook and Twitter.
- National Offender Management Services Monitoring Quality of Prisoner Life (MQPL) survey.
- [Her Majesty's Inspectorate of Prisons \(HMIP\) reports.](#)
- [Independent Monitoring Board data.](#)
- Complaints via the [NHS England Customer Contact Centre](#), and national Ombudsman's reports.
- [Care Quality Commission inspection reports.](#)
- [Ofsted reports](#) (particularly in regard to children and young people's services and settings).
- [Youth Justice Board](#) reports and data sets.
- Local authority reports from Youth Offending Services or Looked after children's services.
- Healthwatch reports.
- Provider networks.
- Local scrutiny committee reports.
- Youth council reports.
- Information from patient representative groups.
- Information from the voluntary sector, in particular organisations with links to specific health and justice services or communities (for example for young people in health and justice settings, consideration should be given not just to youth justice based reports but also information from young people's organisations such as Young Minds, the National Children's Bureau, Action for Children).
- National surveys.
- The [Equality Delivery System](#) for the NHS (EDS2).
- Health and Justice Indicators of Performance (HJIP): Adult Secure Estate User Guide 2015/16
- Health and Justice Indicators of Performance (HJIP): Immigration Removal Centres 2015/16

OFFICIAL

- Health and Justice Indicators of Performance (HJIP): Children and Young Person's Secure Estate 2015/16
- Where available, information in magazines such as Inside Times and Converse (prison settings).
- Case studies.

A number of prisons in the Midlands and East region are piloting a revised approach to the [Friends and Family test](#).

Examples of networks to support patient and public participation:

Network	Local	Regional	National
Liaison and Diversion programme Board			✓
Provider led involvement networks	✓	✓	✓
Voluntary sector involvement infrastructures	✓	✓	✓
Local authority participation infrastructures	✓		
CCG lay member network	✓		✓
Healthwatch	✓	✓	✓
Voluntary and community sector	✓	✓	✓
Clinical Networks		✓	
Health and Wellbeing Boards	✓		
Professional networks (e.g. professional practice based networks)	✓	✓	
Family and Carers networks	✓		✓
Scrutiny networks	✓		✓
Health Education England		✓	✓
Care Quality Commission	✓	✓	✓
Public Health England	✓	✓	✓

C. NHS England guidance and advice

NHS England has developed a range of resources to guide and support commissioners with participation planning and activity.

Teams that can offer support:

- NHS England regional communications and engagement teams and patient experience teams (It should be noted that there is some variability in regional and local arrangements due to structure differences).
- NHS England Public Participation Team in the central support team provides advice and guidance on participation. The team also offers training to commissioners who want to improve their participation skills (available via the NHS internal Learning Management System).
- NHS England central support team advises on equalities and health inequalities (especially when looking at reaching equalities protected groups and groups that experience inequalities in access to services and outcomes).
- NHS England central events team can provide advice and guidance on public events.
- The digital communications team can support commissioners to develop public online surveys and consultations via the [‘Consultation Hub’](#).
- In highly complex and/or high profile situations, it may be necessary to seek legal advice through the NHS England Legal Team and/or specialist communications and engagement expertise through contracted services.
- The NHS England [Publications Control Committee](#) and subsequent Gateway process can help to clarify requirements for published documents.

Web based resources to support participation include the following:

- The [Involvement hub](#) on the NHS England has a range of tools, resources and best practice examples to support participation.
- [Bite size guides to participation.](#)
- [NHS England Patient and Public Voice expenses policy.](#)
- [Templates for recruiting members of the public into participation roles.](#)
- [Smart guides to engagement.](#)
- [‘In Touch’](#) is the patient facing bulletin where events, public consultations and involvement opportunities can be advertised.

External support:

- Commissioning participation support or working in partnership with other organisations with specific expertise is extremely effective.
- Local voluntary sector organisations may have strong existing relationships with local health and justice services (including Healthwatch, service user led organisations and others).
- National organisations have often developed strong forums of user voice.
- Commissioning Support Units.

Case Study:

Healthwatch Peterborough runs a [Prisoner Engagement programme](#). It trains prisoner wellbeing representatives to promote preventative health and wellbeing campaigns to prisoners as well as gathering feedback on health and care services.

D. Engagement approaches for different health and justice settings and communities

D1. People detained in prisons

Context:

There are 123 prisons in England and Wales, 109 of which are managed by HM Prison Service and 14 of which are contracted out to private companies, including Serco, G4S and Sodexo.

Male adult prisoners (those aged 21 or over) are given a security categorisation soon after they enter prison. The four categories are:

- Category A – those whose escape would be highly dangerous to the public or national security.
- Category B – those who do not require maximum security, but for whom escape still needs to be very difficult.
- Category C – those who cannot be trusted in open conditions but who are unlikely to try to escape.
- Category D – those who can be reasonably trusted not to try to escape, and are given the privilege of an open prison.

Women are also classified into four categories. These categories are:

- Restricted Status is similar to Category A for men.
- Closed is for women who do not require Restricted Status, but for whom escape needs to be very difficult.
- Semi-open for those who are unlikely to try to escape.
- Open is for those who can be trusted to stay within the prison.

In February 2016 the government announced a range of prison and youth justice reforms. While the justice estate may change over time, the principles of good service user participation will still apply.

Core principles:

- People in prison have a right to be involved in their healthcare and have a say in shaping and improving the healthcare services that they receive.
- People with recent experience of being in prison can also provide a different perspective of what worked and what didn't with the benefit of hindsight.
- The unique population, culture, regime and range of providers (including healthcare providers) in each prison must be considered when planning engagement with the patient population.
- There can be a barrier of mistrust to engagement that exists between people in prison, especially those who have been in prison on multiple occasions, and people who represent authority such as prison or healthcare staff. Participation activities should take this into consideration.
- The power dynamics of the prison setting mean that people in prison can be less likely to get involved as a result of the potential consequences. Principles such as independence and confidentiality are therefore especially important.
- Participation activities should aim to involve a representative sample of the prison population. Participation activities can attract those who are more

articulate and more compliant. While it is important that these people are involved, they do not always reflect the wider population.

- Families, carers and friends of people in prison should also be consulted with and engaged in this process – please see the section on involving family members and carers.

Practical tips:

1. People in prison have a wide range of restrictions placed on them, such as movement and resources. Participation opportunities need to take account of these in prison settings.
2. People may have restricted access to computers and IT, so mainstream digital involvement approaches are often inappropriate.
3. Many prisons have some existing participation mechanisms in place, such as wing committees, councils and forums, which can be used for healthcare. However, an assessment of whether they adhere to the principles needs to be undertaken before being used.
4. The use of former prisoners to work with current prisoners can be a mechanism to ensure that those often deemed 'harder to reach' are motivated and feel comfortable enough to participate.
5. Access into and around prisons to engage with patients can be very time consuming both in terms of agreeing access in advance (for example, providing personal information and being vetted) and on the day (for example entering, passing through security and moving between wings) so this must be factored into time allocated. Security will always come first and safety of all parties must be paramount. This can impact on a proposed participation activity, sometimes at the last minute (for example, a security lockdown).
6. Commissioners should require healthcare providers to deliver a minimum set of patient participation activities. Patient experience is one of the three key components of quality and needs to be given equal emphasis along with safety and effectiveness. Each local provider will have their own methods of gathering patient feedback.
7. The local healthcare provider can often support and facilitate participation. However, the impact of having healthcare staff present during consultation with patients, needs to be carefully considered, as it will often impact on bias.
8. Commissioners also need to be aware of the risks involved in giving feedback to service providers that might identify prisoners who have given critical feedback.
9. Some local healthcare providers have used the 'friends and family test' to gather feedback on healthcare services in a secure setting. It has been suggested that this will have to be amended to make it fit for purpose, for example, would you recommend this healthcare service if your friend or family were in prison.

Case Study:

User Voice, an ex-offender led charity, was commissioned by the South East Health and Justice Commissioning Team to undertake all patient and public voice (PPV) activities across the region, including 16 prisons. User Voice used its unique user-led approach to recruit and provide accredited training to Peer Researchers in each prison. These Peer Researchers, a paid role within the prison, were tasked with

OFFICIAL

conducting surveys and focus groups to obtain general and more specific feedback on health services. They were given regular peer support by User Voice members of staff, who were former prisoners themselves. A much greater than normal level of information was collected through surveys and focus groups because it was prisoner-led and was supported by a user-led organisation, independent of the prison. This information was given to the commissioners in order to inform different stages of the commissioning cycle.

For example, the Peer Researchers in Lewes Prison were involved in each stage of the procurement process for the new substance misuse service, including:

- Assessing the current commissioned service.
- Contributing to the service specifications.
- Devising questions for tender.
- Evaluating bidder responses.
- Devising questions for bidder interviews.
- Undertaking a service user interview of shortlisted bidders.
- Working with the successful provider to mobilise the new service.

Feedback on this innovative approach, in which service users were central to the procurement process, is provided below.

“I thought that the event was very powerful and produced some rich information. The Service Users did extremely well and were not intimidated by the occasion. They probed the bidders with real issues as well as pre-determined questions. The bidders admitted at the end of the 40 minutes that it was harder that the presentation/clarification with the commissioners at County Hall.”

Mark Hayman, Associate Director of Procurement, South, Central and West CSU Procurement.

Want to learn more?

[The Power Inside: The role of prison councils](#)

D2. Children and Young People in Young Offenders Institutes, Secure Training Centres and Secure Children's Homes

Context:

NHS England commissions services for children and young people (CYP) under the age of 18 who are detained for welfare reasons (under section 25 of the Children Act 1989) as well as those who are sentenced or remanded to custody through the criminal justice service and placed by the Youth Justice Board. There are three types of establishment in the CYP secure estate. Young people are placed in accordance with their needs, taking account of their age, welfare and mental health needs.

- Youth Offender Institutions (YOIs)
- Secure Training Centres (STCs) (Oakhill is not part of NHS provision)
- Secure Children's Homes (SCHs).

There are four YOIs across England supporting young males aged 15 to 18 years old, as well as three Secure Training Centres supporting both males and females aged 12 to 18 years of age. Young people within these settings may be on remand, serving short sentences as well as long sentences including life tariffs. Young people may serve their full sentence at one YOI or move onto the adult estate.

There are 14 Secure Children's Homes across England and Wales supporting young people (male and female) aged 10 to 17 years old. Some SCHs receive only young people who are detained on welfare grounds. Young people may be placed in SCHs if they have significant self-harm issues or a history of absconding. These young people will return to the community once they have received support to address these issues. Some SCHs will accommodate both young people who are detained for welfare reasons and those who are placed by the Youth Justice Board.

Young people who are placed in secure settings by the Youth justice Board may serve their full sentence at the SCH or they may progress to a STC, YOI or eventually move onto the adult estate (dependent upon their sentence). Due to the limited number of establishments, young people are sometimes placed a long distance away from home, this needs to be addressed in resettlement plans.

Core principles:

- Young people in the secure estate need to be involved in their healthcare and have a say in shaping and improving the healthcare services that they receive.
- Involving and working with young people requires adherence to rigorous safeguarding checks and standards. Staff working with young people should have appropriate training and disclosure and barring service (DBS) checks in place and comply with safeguarding policies and procedures.
- Involving young people in the secure estate should be organised well in advance. Planning needs to accommodate a number of regime, timetable and movement restrictions that may be in place.
- Young people in secure settings may not have engaged with health services in the community. In some cases chaotic lifestyles experienced by children and young people can mean that engaging with community services has been inconsistent. As a result of limited engagement in community services,

children and young people can often arrive in secure settings with higher levels of health needs.

- Health and wellbeing services and clinical services should demonstrate integrated planning and communication.
- Planning is required for the release of young people to ensure required health services are accessible on release.
- Be clear about the benefit to young people of any participation work that they are involved in.
- Families and carers should also be engaged – please see section on engaging family members and carers.
- The [June 2013 Healthcare standards for Children and Young People in secure settings](#) (section 9.3 and 9.3.1) specifically set out the requirement to ensure that the views of young people, their parents/carers are sought and taken into account.

Practical tips:

1. Young people may have literacy problems so information needs to be in a simple format and very visual.
2. Advocates work with young people across the secure estate therefore it may be best to link in with them when engaging young people.
3. Young people within the secure estate may not have access to the internet and limited access to computers so this needs to be considered when designing participation.
4. Most secure estate establishments have existing service user forums or participation groups – link in with these existing groups.
5. Forums involving young people need to be short and engaging as young people will become distracted after a short time.
6. If completing questionnaires with young people keep them simple and short and must be something that they can relate to.
7. Any work completed with young people needs to be engaging and snappy in a format that makes sense to them.
8. [‘You’re Welcome’](#), (Department of health standards and guidance on CYP services and settings, 2011) and [‘No decision about me without me’](#) (Department of Health, 2012) provide useful guidelines.
9. Ensure you feedback to young people on how their feedback has been used and thank them for their time.

Case Study

NHS England and Barnardo’s are working in partnership to explore how the voices of children and young people (under 18s) held in secure settings are heard, in relation to the health services they receive. The project also specifically looks at best practice around promoting participation of children and young people in commenting on health services across secure settings in the future.

The project will involve talking to young people to establish how:

- Their experiences are listened to.
- They are visibly involved in improving health services.
- They advise NHS England on issues and challenges impacting on their health.
- They can help NHS England to understand how health services could be organised differently and/or where improvements could be made.

OFFICIAL

D3. Service users of Liaison and Diversion Schemes

Context:

Liaison and Diversion (L&D) services exist to identify offenders who have mental health, learning disability, substance misuse or other vulnerabilities when they first come into contact with the criminal justice system.

These services identify vulnerabilities that offenders may have so that they can either be supported through the criminal system pathway or diverted into a treatment, social care service or other relevant intervention or support service. L&D services aim to improve health outcomes, reduce re-offending and identify vulnerabilities earlier, thus reducing the likelihood that offenders will reach crisis-point.

The L&D national operating model now covers 50% of the population of England with 26 L&D schemes in total. Over 100 police custody suites are covered.

Core principles:

- People with lived experience should be involved in the design and delivery of services that affect them.
- People with lived experience have unique knowledge of how services should be commissioned, designed and delivered to ensure effective engagement and effective and appropriate outcomes
- Lived experience should be both of involvement in the criminal or youth justice system and other vulnerability such as mental health, learning disability, substance misuse, acquired brain injury.
- Lived experience should be recent and, where possible, include knowledge of L&D services.
- Families, carers and friends of people in contact with L&D services should also be consulted with and engaged in this process – please see top tips for consulting with family members and carers.

Practical tips:

- People in contact with L&D services are, very often, in crisis and/or their initial contact may be short-lived. Consider ways of involving and consulting people and collecting feedback once their initial contact has ceased and when any crisis has dissipated.
- Consider setting up parallel systems for people with lived experience to sit alongside other strategic and commissioning arrangements with clear means of communication between the two.
- Where people with lived experience are invited to participate in strategic oversight and other groups there should be at least two members at all times and consideration should be given to supporting them by a voluntary and community sector (VCSE) organisation or service user group.
- Traditional methods of collecting feedback information on L&D services (for example the Friends and Family Test) are unlikely to translate into criminal and youth justice settings. Collecting such information may need to be delayed until someone's involvement with the justice process has ceased.
- VCSE and service user groups should be engaged to collect feedback on services as well as to undertake consultations with individuals about the effectiveness and design of services.

Case study

At a national level the L&D Programme Board has established a Lived Experience Team (LET) to consult with and provide feedback on the national programme. The LET has been instrumental in advising on revisions to the national L&D operating model and in developing models of peer support and assurance. The LET both meets on its own to discuss key issues and board papers as well as attending board meetings supported by the [Revolving Doors Agency](#) as part of the [Offender Health Collaborative](#) to provide direct input into decisions about the design and delivery of the programme.

At a local level the Avon and Somerset L&D Project Board has service user representatives as key and equal members to advise on mobilisation and delivery. One positive outcome was the feeling that the language at meetings was less 'jargony' and the agenda more service user focused. One service user representative was reported to be very positive about the experience, and found it particularly powerful attending a meeting in a court room, given last time she had been in court it was for sentencing. The Lead Practitioner said: "Meetings can get very fixed upon organisational issues (and I'm guilty as charged), and lose sight of core service aims i.e. the needs of service users. While it'll take a bit of time to quantify any direct impact upon service provision, having service user representative input has changed the culture of the partnership board, and that's a good thing." (John Meacock, Avon and Somerset L&D Service).

In Sussex, the L&D service has included an additional question as part of the consent form to gather and share information. It asks if people would be willing to be consulted at a later date to provide feedback on delivery and assist in the design of future services.

Want to learn more?

For further information about L&D please visit the [health and justice section of the NHS England website](#).

You can read [a copy of the L&D manager and practitioner briefing on service user engagement](#).

D4. Service users from black, Asian and minority ethnic communities

Context:

People from most black, Asian and minority ethnic (BAME) communities are disproportionately represented, and experience poorer outcomes, at every stage of the Criminal Justice System. For example, 26% of the prison population of England and Wales are from BAME groups, compared to 14% of the general population. BAME representation is also heavily influenced by age, with many more young BAME male prisoners than older ones; and in the youth estate, 43% of 15-17 year olds coming from such backgrounds. Many BAME communities also experience a range of health inequalities, which can affect their interaction with healthcare services and the health outcomes they receive.

Core principles:

- People from BAME communities have a right to be involved in their healthcare and have their voices heard.
- Be aware of the diverse people and voices that make up BAME groups, for example, BAME women, children and cultural groups who represent multiple marginalised identities.
- Negative experiences of differential treatment and stereotyping can lead to an even greater lack of trust in services among people from BAME groups than for the offender population in general.
- Stigma and discrimination can exist where there is a lack of understanding of the culture and needs of others. Involvement activities should be delivered by culturally competent staff and take into account individuals' cultural backgrounds and needs.

Practical tips:

1. Work with local and national BAME-led organisations to involve and build trust with service users from different communities.
2. When recruiting people to involvement opportunities, actively target those from seldom heard groups to ensure you are involving a wide range of service users.
3. Make information available in a range of formats and languages.
4. Ensure staff are trained in cultural awareness, and have the skills to manage different service user voices in a group.
5. Use peer researchers or reviewers to elicit honest/open feedback from service users from a similar cultural background.
6. Use creative activities and the arts to provide a space for people to explore complex issues.

Case study - 300 Voices

In January 2013, Birmingham and Solihull Mental Health NHS Foundation Trust, West Midlands Police and Birmingham City Council partnered with Time to Change to develop the [300 Voices project](#) to engage with young African and Caribbean men, aged between 18 and 25, to hear their experiences of inpatient and outpatient care. The project aimed to bring young African and Caribbean men together with mental health professionals to explore - through open conversation - their experiences of accessing mental health services, the stigma that often exists, and how steps can be taken to move forwards, towards a better experience for those young men. At facilitated engagement sessions, service users tell their stories through a range of

formats; staff are then encouraged to share their experiences of working with this group; followed by a time of dialogue and action planning to contribute towards ongoing transformation of the relationship between young African and Caribbean men and mental healthcare professionals.

Want to learn more?

[The Young Review](#)

[Tackling Inequality in the Criminal Justice System](#)

[Bradley Commission briefing on Black and Minority Ethnic communities, mental health and criminal justice](#)

[Black Training and Enterprise Group](#)

[Race Equality Foundation](#)

D5. Older offenders

Context:

Older offenders are the fastest growing age group in the prison estate. People in contact with the Criminal Justice System often present with health needs up to 10 years earlier than would be expected in the general population; so older prisoners are usually defined as those over the age of 50. This group currently makes up 14% of the prison population. Many experience chronic health problems prior to or during imprisonment as a result of poverty, poor diet, inadequate access to healthcare, alcoholism, smoking and other substance abuse. The psychological strains of prison life can further accelerate the ageing process. [Source: Prison Reform Trust (2015), Bromley Briefings Prison Factfile Autumn 2015]

Core principles:

- Older offenders suffer from distinct health needs that need to be considered when designing and delivering health and care services in the justice system.
- Older prisoners may suffer from a lack of confidence, and/or from age-related cognitive decline, meaning their voices are not heard and their needs are unaddressed unless dedicated formal consultation processes for them are in place.
- Integration of health and care support is of particular importance in maintaining the wellbeing of older prisoners.
- Involving family members in care planning and discussions or decisions around healthcare is also vital, especially where older prisoners may be suffering from age-related cognitive decline, such as dementia.

Practical tips:

1. Work with existing groups to consult with older offenders. For example, many prisons have Older Prisoner Forums, or special activity groups for older people; and some probation Community Rehabilitation Companies have dedicated teams working with older people.
2. Look for simple solutions! Consult with patients and ask their views to ensure that you're addressing actual rather than perceived needs.
3. Involve family members to gather their views on healthcare for older offenders.

Case study

In one prison, staff reported that the older prisoners were reluctant to shower, and that this was becoming a hygiene issue. This was discussed at the older prisoners' forum run by Recoop, where it emerged this was because the time given to get to and from the showers was not sufficient for older prisoners with mobility issues. The prisoners came up with the solution of being provided with dressing gowns, allowing them to undress and dress in their cells, and to move between the cells and the showers with dignity within the allotted time. Once implemented all the men were showering regularly.

Want to learn more?

[Recoop](#)

[Restore Support Network](#)

[Tackling Inequality in the Criminal Justice System](#)

D6. Victims and survivors of rape and sexual assault (users of Sexual Assault Referral Centres)

Context:

There are approximately 85,000 women and 12,000 men raped in England and Wales alone every year.

- Nearly half a million adults are sexually assaulted in England and Wales each year.
- 1 in 5 women aged 16 - 59 has experienced some form of sexual violence since the age of 16.
- Only around 15% of those who experience sexual violence choose to report to the police.
- Approximately 90% of those who are raped know the perpetrator prior to the offence.

[Source: [An Overview of Sexual Offending in England and Wales](#), the first ever joint official statistics bulletin on sexual violence released by the Ministry of Justice (MoJ), Office for National Statistics (ONS) and Home Office in January 2013.]

Sexual abuse and violence is described as:

'Any sexual act, attempt to obtain a sexual act, unwanted sexual comments or advances, or acts to traffic, or otherwise directed, against a person's sexuality using coercion, by any person regardless of their relationship to the victim, in any setting, including but not limited to home and work'. [Krug, E., Dahlberg, L. Mercy, J. Zwi, A. and Lozano, R. (2002) World Report on Violence and Health, Geneva: World Health Organisation, p149].

Those most vulnerable to sexual abuse and violence tend to be those who are already experiencing social disadvantage and oppression. These are also groups that are more difficult for agencies to reach, and about whom there is less research:

- Children and young people;
- Young men and young women;
- Young women and young men abused through prostitution;
- Homeless populations;
- Adults in institutional care;
- Disabled women and men;
- Lesbian, gay, bisexual and transgender adults;
- Refugees and asylum seekers;
- Prison populations.

Sexual abuse and violence are major sources of distress and harm, with negative consequences for the health and wellbeing of countless women, men, boys and girls across the UK.

Sexual Assault Referral Centres (SARCs) offer:

- Crisis support in response to recent sexual assaults;
- Medical interventions and forensic facilities for those who opt to report the offence/s against them;
- Fast track referral to sexual health services;
- Specific services for children and young people, including specialised mental health assessments and support;
- Services addressing the safeguarding needs of children and young people (and other vulnerable groups).

SARCs may also:

- Offer short term counselling and Independent Sexual Violence Advisor services;
- Accept self-referrals.

Core principles:

- Victims and survivors of sexual violence and abuse have a right to access health care including referral to sexual health services, sexual assault referral centres, specialist counselling and support.
- Survivors repeatedly say they want well-informed services that have a comprehensive understanding of the impact of sexual violence.
- Good services are those that recognise the issue is trauma not an illness or those that identify the root cause of a disorder (for example an eating disorder) may be sexual violence or sexual abuse, rather than a mental health problem.
- The majority of people referred to or approaching SARCS will be experiencing some sort of response to trauma, be it the result of a recent assault or a more deep-rooted behaviour pattern born out of coping with experiences of childhood sexual abuse. For this reason, an effective service response will be trauma informed, and have an understanding of the impact of sexual violence on survivors' communication and behaviour.
- Recent research highlights the poor response many victims and survivors have received from health and social care services.

Practical tips:

1. Victims and survivors have experienced trauma and may need additional support to engage with participation processes, including the presence of a supporter.
2. Involving local voluntary sector specialist sexual violence and sexual abuse support services, will contribute to their local knowledge and experience of survivors and will also strengthen referral pathways into their services.
3. Victims and survivors are victims of criminal offences and services need to be aware of managing evidence, including first disclosure, which could involve a staff member giving evidence in a criminal trial.
4. Consultation work with survivors and offenders should be kept separate. This delineation is usually described in the governance of SARCs.
5. It may not be appropriate to involve a victim/survivor if there is an ongoing criminal justice process. The Investigating Officer or the Crown Prosecution Service (CPS) in the case would be able to advise if necessary.

6. Victims and survivors are often concerned about confidentiality and may not want information about the offences against them shared with other services or professionals.
7. Victims and survivors have suffered an extreme boundary violation and it is crucial for them to have open and transparent communications and to be offered informed choices.
8. Victims and survivors may be suffering from symptoms of Rape Related Post Traumatic Stress Disorder (PTSD) or Complex PTSD and communications need to take this into account; using plain language, clear explanations and repeating information where needed.
9. Consultation processes need to take into account the potential to retrigger trauma responses when someone is asked about traumatic experiences; checking for ongoing support networks and ensuring participants are fully informed and aware will mitigate this risk.
10. When bringing together victims and survivors for participation events, organisers need to be aware that there is a natural tendency for some victims and survivors to share detail of their experiences. Ensuring there are sufficient supporters and facilitators will make this process easier to manage and safer for participants.
11. Previous feedback from participants in consultations shows that victims and survivors are generally keen to contribute their experiences and many feel very positive about supporting consultations.

Case study

The Survivors' Trust and Rape Crisis England and Wales worked together to host a conference where victims and survivors of sexual violence and sexual abuse, specialist voluntary sector sexual violence and abuse support services and NHS England Commissioners could explore experiences of health services - what good services looked like and how they could be commissioned effectively. They worked together to develop the delegate list and conference programme. A total of 50 victims and survivors of rape, sexual violence and sexual abuse, 50 specialist voluntary sector service providers and 10 NHS England Regional Leads and Commissioners attended the conference. Presentations were delivered by a female rape survivor, a female childhood sexual abuse survivor and a male survivor of childhood sexual exploitation. Two specialist voluntary sector services also delivered presentations giving an overview of their services and experiences of local commissioning processes.

A Conference Report was produced in collaboration between The Survivors Trust and Rape Crisis England and Wales: Survivors' Journeys, Survivors' Voices. The Report has been circulated to all Clinical Commissioning Groups (CCGs) by NHS England. Feedback from participants was very positive, with numerous requests to be involved in similar events.

D7. Adult survivors of childhood sexual abuse, rape and sexual assault

Context:

Health and justice Sexual abuse and violence includes: child sexual abuse, sexual assault, rape, sexual exploitation, forced marriage, honour based violence, trafficking of women and children, online grooming of children, use of digital information and communication technologies to perpetrate sexual violence.

The impact of sexual violence and sexual abuse will vary from person to person and may affect mental, emotional, sexual and physical health and wellbeing. Short term responses may include shock, shame, misplaced guilt as well as physical injury. Longer term impacts can include hyper-vigilance, exaggerated startle response, perceiving threats all around, anxiety, depression, agoraphobia or claustrophobia, low self-esteem, self-medication, self-harming behaviours, suicidal behaviour and thoughts, dissociation and post-traumatic stress symptoms or disorder (PTSD), which is diagnosed where there is a continuation of these symptoms. Inevitably, all of these can have an impact on a survivor's ability to work, form relationships, parent, carry out daily tasks or self-care.

Sexual violence and sexual abuse is a gendered issue with many more female victims than males. However there are significant numbers of male victims of childhood sexual abuse and exploitation who often face increased barriers to disclosing the offences against them.

Sexual abuse and violence are major sources of distress and harm, with negative consequences for the health and wellbeing of countless women, men, boys and girls across the UK.

Many survivors cope with their distress alone, too frightened or ashamed to tell the police, friends or partners: many never find sources of support that would promote recovery or achieve justice. Many survivors are contending with harm caused through sexual abuse and violence and through other forms of oppression and violence. The individual and social costs for adults and children are extremely high, particularly where there is multiple or repeat victimisation.

Independent dedicated specialist sexual violence organisations offer:

- Medium and longer term specialist counselling and therapeutic support to survivors who have experienced sexual abuse or sexual violence **at any point in their lives**. This includes adult survivors of child sexual abuse;
- Crisis support, including advocacy;
- Work on awareness raising and prevention of sexual violence;
- Community based support in both rural and urban locations.

The Council of Europe Minimum Standards defines 'specialist' as 'provision of services by staff and volunteers with the appropriate skills and expertise to deliver tailored services to survivors with complex needs'.

Core principles:

- Victims and survivors of sexual violence and abuse have a right to access healthcare including referral to sexual health services, sexual assault referral centres, specialist counselling and support.
- Research shows that victims and survivors are accessing a full range of health and mental health services but may not have disclosed that they have been sexually abused or raped.
- In engaging with victims and survivors, consideration needs to be given to the varying needs and how these can be accommodated – for example women only or male only spaces, need for advocates or supporters to be involved, hearing loops and language barriers.
- Victims and survivors repeatedly say they want well informed services that have a comprehensive understanding of the impact of sexual violence.
- Good services are those that recognise the issue is trauma not an illness, or those which identify the root cause of an eating disorder may be sexual violence or sexual abuse, rather than a mental health problem.
- Do not medicalise survivors' reactions by diagnosing individuals and then seeking to 'treat' them. Instead, support them to regain control and work towards recovering from their experiences of rape and/or sexual abuse.
- Survivors value a calm, non-clinical setting and for services to take a holistic approach to meeting their needs.
- Survivors are individuals and want to be treated as such.
- Having more knowledge about sexual violence, sexual abuse and the dynamics of abuse increases their ability to:
 - Protect themselves or their children;
 - Feel more in control;
 - Feel safe;
 - Increase self-care;
 - Develop more positive coping mechanisms.

Practical tips:

1. Victims and survivors are often concerned about confidentiality and may not want information about the offences against them shared with other services or professionals.
2. Victims and survivors have suffered an extreme boundary violation and it is crucial for them to have open and transparent communications and to be offered informed choices.
3. Victims and survivors may be suffering from symptoms of Rape Related PTSD or Complex PTSD and communications need to take this into account; using plain language, clear explanations and repeating information where needed.
4. Victims and survivors may need additional support to engage with consultation processes, including the presence of a supporter.
5. Consultation processes need to take into account the potential to retrigger trauma responses when someone is asked about traumatic experiences; checking for ongoing support networks and ensuring participants are fully informed and aware will mitigate this risk.
6. Involving local voluntary sector specialist sexual violence and sexual abuse support services, will contribute to their local knowledge and experience of survivors and will also strengthen referral pathways into their services.

7. When bringing together victims and survivors for consultation events, organisers need to be aware that there is a natural tendency for some victims and survivors to share their experiences. Ensuring there are sufficient supporters and facilitators will make this process easier to manage and safer for participants. It is also important to consider space for time out for victims and survivors who may become distressed, such as a private room.
8. Victims and survivors are victims of criminal offences and services need to be aware of managing evidence, including first disclosure, which could involve a staff member in giving evidence in a criminal trial.
9. It may not be appropriate to involve a victim/survivor if there is an ongoing criminal justice case in progress as meetings with other victim/survivors may be seen as contaminating evidence. The Investigating Officer or the CPS in the case would be able to advise if necessary.
10. Previous feedback from participants in consultations shows that victims and survivors are generally keen to contribute their experiences and many feel very positive about supporting consultations.

Case study

The Survivors' Trust set up a Survivors' Forum to provide input into the commissioning cycle, development of services for victims and survivors of sexual violence and abuse in London, and monitoring processes. Recruitment was conducted through contact with member agencies of The Survivors' Trust offering specialist counselling and support to victims and survivors in London. This approach was taken to ensure that participants were in contact with a specialist service and had access to ongoing support if this was needed. It was decided not to restrict the Forum to one specific experience of sexual violence or abuse so that it reflected the client groups accessing the services.

The venue for the Forum was chosen as a central London charity providing specialist counselling and therapy for victims and survivors of sexual violence and abuse. Fifteen participants were recruited in all, comprising nine women and seven men. One participant with a learning disability requires a supporter to attend meetings. Two meetings have been held and the group has developed terms of reference and an outline work plan which includes meeting with commissioners and visiting local NHS specialist services.

Want to learn more?

- (1) Smith, Noel, Dogaru, Christian and Ellis, (2015) *Fiona Hear Me, Believe Me, Respect Me. A survey of adult survivors of child sexual abuse and their experiences of support services*, University Campus Suffolk.
- (2) Astbury, J. (2006) *Services for Victims/survivors of Sexual Assault*, Australia: Australian Institute of Family Studies.
- (3) Bunting, L. (2005) *Females who Sexually Offend Against Children: Responses of the Child Protection and Criminal Justice Systems*, London: NSPCC.
- (4) O'Leary, P.J. and Barber, J. (2008). 'Gender differences in silencing following childhood sexual abuse', *Journal of Child Sexual Abuse*, 17 (2) p133 – 143.
- (5) Sen, P. and Kelly, L. (2007) *CEDAW Thematic Shadow Report on Violence Against Women in the UK*. London.

OFFICIAL

- (6) HM Government (2006) Working Together to Safeguard Children, London: Stationery Office.
- (7) Lievore, D. (2003) Non Reporting and Hidden Reporting of Sexual Assault in Australia, Canberra: Australian Institute of Criminology.
- (8) Kelly, L and Lovett, J. (2009) Different Systems, Similar Outcomes: Tracking Attrition in Reported Rape Cases in 11 Countries, London: CWASU.
- (9) Kelly, L., Lovett, J. and Regan, L. (2005) A Gap or a Chasm? Attrition in Reported Rape Cases, London: Home Office Research, Development and Statistics Directorate.
- (10) Dennis, M., Foold, A., Reynolds, V., Araujo, C., Clancy, P., Barefoot, C. and Beckham, J. (2009) 'Evaluation of lifetime trauma exposure and physical health in women with PTSD or major depressive illness', Violence Against Women, 15, p618 – 627.
- (11) Sar V, Akyuz G. and Kundakci T. (2004) 'Childhood trauma, dissociation, and psychiatric co-morbidity in patients with conversion disorder', American Journal of Psychiatry, 161(12):2271-6.
- (12) Acierno, R., Resnick, H.S. and Kilpatrick, D.G. (1997) 'Health impact of interpersonal violence: Prevalence rates, case identification, and risk factors for sexual assault, physical assault, and domestic violence in men and women', Behavioural Medicine, 23, p53-64.
- (13) McGee, H., Garavan, R., de Barra, M., Byrne, J. and Conroy, R. (2005) SAVI and SAVI revisited: Sexual abuse and violence in Ireland, Dublin, Dublin Rape Crisis.
- (14) Report of the Independent Review into The Investigation and Prosecution of Rape in London Rt Hon Dame Elish Angiolini DBE QC. 30 April 2015
- (15) The full report, Sexual abuse and violence in the UK: Report of a pilot study, by Christine Harrison, Robyn North and The Survivors' Trust is available as a free download from [The Survivors' Trust website](#). The website also gives information about sexual abuse and violence services in the UK and about other relevant reports and publications.

D8. Children and young people who are victims and survivors of rape and sexual abuse

Context:

More than one third (39%) of all rapes recorded by the police in England and Wales in 2012/13 were committed against children under 16 years of age.

'Sexual abuse involves forcing or enticing a child or young person to take part in sexual activities, including prostitution, whether or not the child is aware of what is happening. The activities may involve physical contact, including penetrative or non-penetrative acts. They may include non-contact activities such as involving children in looking at or in the production for sexual online images, watching sexual activities, or encouraging children to behave in sexually inappropriate ways.'

At least 16% of children in the UK experience one or more of these forms of sexual abuse; although a number of studies indicate even higher levels. In more than a third of police recorded rapes the victim was under 16.

The majority of perpetrators of child sexual abuse are heterosexual men. In most cases of child sexual abuse the perpetrator is known to the victims, but not in the immediate family. Offenders often target children and mothers/carers that they perceive as vulnerable and they may adopt strategies (including bribes and threats) to ensure that children do not tell, or are disbelieved if they do. The NSPCC found that 72% of children and young people who have experienced abuse did not tell anyone at the time; 31% still had not told anyone by adulthood.

Over recent years, the extent of abuse involving digital information and communication technologies has increased exponentially, and there is greater awareness of child trafficking and the abuse of children through prostitution. Furthermore there are higher levels of sexual abuse of disabled children, children missing from home and children who are looked after.

For children and young adults, the immediate effects of an assault (shock, powerlessness, helplessness, acute psychological distress) may subside over time. Other feelings, of anxiety, fear, and depression, may last for a considerable period of time and contribute to poorer mental health, low self-esteem and suicidal thoughts, or manifest in eating disorders and self-harm.

At their most intense, symptoms may indicate Post Traumatic Stress Disorder, experienced by a high proportion of women survivors. Dissociative Identity Disorder may also result from extreme sexual abuse in childhood - the use of dissociation, functional amnesia and depersonalisation are important survival strategies when trying to live through unendurable circumstances.

Physical injuries and poorer physical health may also result from sexual abuse and violence, including a higher incidence of cancer, gynaecological problems, heart disease, respiratory disease, gastrointestinal problems, or irritable bowel syndrome. Sexual abuse also has an impact on the victim's family members and carers.

Victims of childhood abuse have been found to wait from between nine to 16 years before disclosing trauma with many never disclosing [Frenken & Van Stolk, 1990; Anderson, Martin, Mullen, Romans & Herbison, 1993; Read, McGregor, Coggan & Thomas, 2006].

Many survivors cope with their distress alone, too frightened or ashamed to tell the police, friends or family: many never find sources of support that would promote recovery or achieve justice. Many survivors are contending with harm caused through sexual abuse and violence and through other forms of oppression and violence. The individual and social costs for young people and children are extremely high, particularly where there is multiple or repeat victimisation.

Core principles:

- Children and young people who are victims and survivors of sexual violence and abuse have a right to access healthcare including referral to sexual health services, sexual assault referral centres, specialist sexual violence and abuse counselling and support.
- It is important for children and young people to feel believed and listened to; it is of significant importance to build rapport and trust with the individual.
- Engagement activities with children and young people needs to take in to account safeguarding policies and protocols, appropriate staff skills and training and any additional support that might be needed following engagement activities.
- Involving parents/carers and siblings is helpful in supporting children and young people to engage.
- Research shows that victims and survivors are accessing a full range of health and mental health services but may not have disclosed that they have been sexually abused or raped.
- In engaging with children and young people, consideration needs to be given to the varying needs and how these can be accommodated – for example flexibility in where and when meetings take place, need for parents/carers to be involved, need for independent support or advocacy, hearing loops, language barriers and literacy levels.
- Victims and survivors repeatedly say they want well-informed services that have a comprehensive understanding of the impact of sexual violence.
- Good services are those that recognise the issue is trauma not an illness, or those that identify the root cause of an eating disorder may be sexual violence or sexual abuse, rather than a mental health problem.
- Recognising developmental stages and the different impact trauma may have at each stage is important in engaging effectively with children and young people.
- Children and young people will benefit from a calm, non-clinical setting and for services to take a holistic approach to meeting their needs.
- Children and young people are individuals and want to be treated as such.
- Having more knowledge about sexual violence, sexual abuse and the dynamics of abuse and increases their ability to:
 - Protect themselves;
 - Support friends;
 - Cope;
 - Feel more in control;

OFFICIAL

- Feel safer;
- Increase self-care;
- Develop more positive coping mechanisms.

Practical tips:

1. Children and young survivors have feelings of guilt and fear of the consequences of disclosure; it is therefore vital they are supported to feel safe and not judged.
2. Victims and survivors are often concerned about confidentiality and may not want information about the offences against them shared with other services or professionals.
3. Victims and survivors have suffered an extreme boundary violation and it is crucial for them to have open and transparent communications and to be offered informed choices.
4. Children and young people may be suffering from trauma symptoms or PTSD, which has not been recognised. Communications need to take this into account; using plain language, clear explanations and repeating information where needed.
5. Children and young people may need additional support to engage with consultation processes, including the presence of a supporter.
6. Consultation processes need to take into account the potential to retrigger trauma responses when asking about traumatic experiences. Involving non-abusing parents/carers and ensuring participants are fully informed and aware will mitigate this risk.
7. Involving local voluntary sector specialist sexual violence and sexual abuse support services, will contribute their local knowledge and experience of survivors and will also strengthen referral pathways into their services.
8. When bringing together victims and survivors for consultation events, organisers need to be aware that there is a natural tendency for some victims and survivors to share their experiences. Ensuring there are sufficient supporters and facilitators will make this process easier to manage and safer for participants.
9. Victims and survivors of criminal offences and services need to be aware of managing evidence, including first disclosure, which could involve a staff member giving evidence in a criminal trial.
10. Children and young people may feel disempowered if safeguarding procedures are followed without involving them sufficiently to ensure they understand the process. Failure to do this may result in the child or young person disengaging from services, retraction of disclosures or further vulnerability to abuse.
11. It may not be appropriate to involve a victim/survivor if there is an ongoing criminal justice case progress as meetings with other victim/survivors may be seen as contaminating evidence. The Investigating Officer or the Crown Prosecution Service in the case would be able to advise if necessary.
12. Previous feedback from participants in consultations shows that victims and survivors are generally keen to contribute their experiences and many feel very positive about supporting consultations.

***Case study - Routine Enquiry into Adversity in Childhood (REACH) Partner Event:
Department of Health Pathfinders Project***

In 2013, Lancashire Care NHS Foundation Trust (LCFT) developed a model for Routine Enquiry about Adversity in Childhood (REACH); a programme designed to develop the skills and confidence of professionals to routinely ask about adverse childhood experiences, such as sexual abuse. The team are currently working on a pathfinder for the Department of Health to adapt this process of enquiry for young people from 14 years onwards. This has involved consultation with young people, including survivors' groups to make sure the approach is sensitive and effective for this population.

The aim is to provide opportunities for young people to feel able to talk about their experience of abuse and to ensure professionals understand how best to respond to their needs.

We hope that this will enable services to offer earlier and more targeted support, producing more positive outcomes for services and service users and encouraging organisational culture change across the UK.

Outcomes:

- Potential to stop the intergenerational impact of Adverse Childhood Experiences (ACEs) and better target root cause– fix problems once.
- More disclosures of childhood abuse coming forward.
- Improved awareness of the issues.
- Preventative/safeguarding opportunities.
- Generate zero tolerance of the issues within society.
- Acceptance that childhood abuse does happen.
- Useful tool for data collection.

Want to learn more?

[Keep them safe – protecting children from child sexual exploitation course](#)

[Future in Mind Report 2015](#) – Promoting, protecting and improving our children and young people's mental health and wellbeing.

National Institute for Health and Care Excellence (2014)

- Experiencing or witnessing violence and abuse or severe neglect has a major impact on the growing child and on long term chronic problems into adulthood.
- Ensuring assessments carried out in specialist services include sensitive enquiry about neglect, violence and physical, sexual or emotional abuse. For young people aged 16 and above, as part of the Government's response to the concerns arising about child sexual exploitation, routine enquiry in line with NICE guidelines (whereby every young person is asked during the mental health assessment about violence and abuse) will be introduced from 2015-16.

[Tackling Child Sexual Exploitation Report March 2015](#)

This report recommended that the routine enquiries made by professionals in targeted services, such as mental health, sexual health and substance misuse services, should be expanded to include questions about child abuse, to help ensure early intervention, protect those at risk and to ensure victims receive the care they need.

Collings, S. J. (1995). "The long-term effects of contact and non-contact forms of child sexual abuse in a sample of university men": *Child Abuse and Neglect*: 19: 1-6.

Bunting, L. (2005) *Females who sexually Offend Against Children: Responses of the Child Protection and Criminal Justice Systems*, London: NSPCC.

O'Leary, P.J. and Barber, J. (2008). 'Gender differences in silencing following childhood sexual abuse', *Journal of Child Sexual Abuse*, 17 (2) p133 – 143.

Sen, P. and Kelly, L. (2007) *CEDAW Thematic Shadow Report on Violence Against Women in the UK*. London.

Adverse Childhood Experiences Study (ACE Study) Felitti et al 2014.

Future in Mind Report 2015 – Promoting, protecting and improving our children and young people's mental health and wellbeing. National Institute for Health and Care Excellence (2014). NICE public health guidance 50.

HM Government (2006) *Working Together to Safeguard Children*, London: Stationery Office.

HM Government (2007) [Cross Government Action Plan on Sexual Violence and Abuse](#).

Lievore, D. (2003) *Non Reporting and Hidden Reporting of Sexual Assault in Australia*, Canberra: Australian Institute of Criminology.

Home Office Research, Development and Statistics Directorate.

Dennis, M., Foold, A., Reynolds, V., Araujo, C., Clancy, P., Barefoot, C. and Beckham, J. (2009) 'Evaluation of lifetime trauma exposure and physical health in women with PTSD or major depressive illness', *Violence Against Women*, 15, p618 – 627.

Sar V, Akyuz G. and Kundakci T. (2004) 'Childhood trauma, dissociation, and psychiatric co-morbidity in patients with conversion disorder', *American Journal of Psychiatry*, 161(12):2271-6.

McGee, H., Garavan, R., de Barra, M., Byrne, J. and Conroy, R. (2005) *SAVI and SAVI revisited: Sexual abuse and violence in Ireland*, Dublin, Dublin Rape Crisis.

The full report, *Sexual abuse and violence in the UK: Report of a pilot study*, by Christine Harrison, Robyn North and The Survivors' Trust is available as a free download from [The Survivors' Trust website](#). The website also gives information about sexual abuse and violence services in the UK and about other relevant reports and publications.

D9. Service users in Immigration Removal Centres

Context:

Home Office Immigration Enforcement operates immigration removal centres (IRCs) and short term holding facilities (STHFs), both residential and non-residential, which are used for some people and families whose right to residence is questioned, or whose departure from the UK is being enforced. The statutory purpose of these detention facilities is to provide secure but humane accommodation of detained persons whilst case owners take action to process asylum cases or seek to remove from the UK. This includes:

- People who have just arrived in the UK and who are subject to examination by an immigration officer to decide whether or not they can be granted entry to the UK;
- People who have entered the UK illegally who are waiting for a decision as to whether they will be granted leave to enter, and who are waiting for removal if leave to enter is refused. This category may include people who have applied for asylum;
- People who have overstayed their limited leave to remain, or who have breached conditions attached to their leave to remain, and who are waiting for a decision about whether they are to be removed from the UK, or pending their removal; and
- People against whom the Home Office is taking deportation action. Most people in this position will be foreign national offenders who have completed their criminal sentence.

Of the 3,483 people in detention as at the end of March 2015, 3,178 were male and 305 were women. Most people detained under immigration powers spend only very short periods in detention, with 63% leaving detention with 29 days and 93% leaving within 4 months⁵.

Since 2013, NHS England has had commissioning responsibility for health provision across the IRC estate (though this was delegated to the Home office during 2013). The national operating standard for healthcare in IRCs states that 'All detainees must have available to them the same range and quality of services as the general public receives from the National Health Service'.

All detainees are seen for a healthcare screening assessment on arrival. Detainees can then access healthcare facilities on demand, subject to a triage service similar to those found in GP surgeries in the community. NHS England is also responsible for commissioning secondary care, dentistry, optician and public health services across the detained settings (including disease surveillance and the prevention of disease outbreak and substance misuse services within IRCs). Detainees should expect continuity of care between establishments, and with community services as permitted, if given leave to remain in the UK or otherwise released from detention.

⁵ [Health and wellbeing needs assessment programme: national summary report](#)

Core principles:

- People in the IRC estate should be involved in their healthcare and have a say in shaping and improving the healthcare services that they receive.
- People in the IRC estate are detained for the period of time that it takes to decide their case. This means that there is an undetermined length of stay for detainees. The population frequently has a short period of detention that is often characterised by frustration and anxiety.
- The rapid turnover and short duration of detainees in the IRC system can make the opportunities to engage challenging.
- There can be a barrier of mistrust to engagement that exists between people in IRCs and people who represent authority such as IRC or healthcare staff. Participation activities should be aware of this.
- The power dynamics of IRC settings mean that detainees can be less likely to get involved as a result of the potential consequences. Working through independent intermediaries, such as volunteers or third sector organisations and principles of anonymity and confidentiality are therefore especially important.
- Participation activities should aim to involve a representative sample of the detainee population. Participation activities can attract those who are more articulate and more compliant. While it is important that these people are involved, they do not always reflect the wider population.
- Anxiety and depression are more prevalent among these populations e.g. experience of trauma, stress related to immigration status.
- Detainees may have some restrictions placed on them, so involvement opportunities need to take account of delivering these in restricted settings (rather than out in the community). Planning for workshops/focus groups can take additional time.
- People may have restricted access to computers and IT, so mainstream digital involvement approaches may be inappropriate.
- Good service user involvement is vital and it is important that an effective way to obtain the views of detainees is found on an ongoing basis if accurate data gathering on health needs is to be obtained over time.

Practical tips:

1. Most detainees are men under 30, but it is important to recognise that there are also female and older detainees, and it is important to seek views from women and children. Participation methods should take account of the target group.
2. Many detainees may experience language or additional communication barriers (they may have limited reading and writing skills in English, or overall literacy). Creative visual or aural approaches can be useful.
3. The IRC population has higher mental or emotional wellbeing needs identified. This can impact on people's ability to engage. It is important to consider a range of approaches and opportunities, for example anonymous digital surveys, focus groups, creative sessions and questionnaires.
4. Use any existing participation forums.
5. Work in partnership with independent and voluntary sector organisations.

6. IRC services are subject to independent inspection (by for example CQC, HM Inspectorate of Prisons and Independent Monitoring Boards). Working with, or drawing insight from, independent scrutiny organisations can provide useful intelligence.
7. Review complaints data.

Case study

In May 2015 NHS England published a Health and Wellbeing Needs Assessment (HWBNA) report for IRCs. The report sought to develop a national picture of health need and activity across the IRC estate. The report authors used a variety of data sources to inform their work. This included data from:

- Her Majesty's Inspectorate of Prisons (HMIP) Reports.
- Independent Monitoring Board Reports and healthcare monitoring data from the individual establishments.
- More than 70 healthcare and IRC staff were interviewed and more than 170 staff responded to questionnaires.
- 92 detainees were interviewed; focusing on their experience of services and their suggestions for change.
- Additionally 120 questionnaires were received from detainees.

The HWBNA report was able to identify a number of areas for improvement:

- The use of a standardised assessment form that moves with the detainee with any establishment move.
- The need for more focus on mental and emotional health needs.
- The need for more data in respect of people with learning disabilities in IRCs.
- A desire from detainees for improved access to family and friends.

Want to learn more?

[Health and Wellbeing Health Needs Assessment Programme: Immigration Removal Centres and Residential Short Term Holding Facilities National Summary Report May 2015](#)

[Information on immigration detention statistics](#)

D10. Involving families and carers

Context:

There are around 85,500 people being held in prisons in England and Wales. Families of offenders and prisoners are often hard to identify, often because they do not want to openly disclose that they have a relative in prison or on probation, however it is estimated that over 200,000 children are affected by imprisonment at any one time - more children experience a parent going to prison each year than a parent getting divorced.

[Source: [Prisoners' childhood and family backgrounds, London: Ministry of Justice, 2012](#)]

- Two-thirds of imprisoned women are mothers with children under the age of 18. A third of these women have children under the age of five, and a further 40% have children aged between five and 10. [Source: [Sentencing Mothers, Prison Reform Trust 2015](#)].
- Prisoners' families are likely to experience financial instability, poverty, debt and potential disruption to their housing situation when a family member is in prison. [Source: [Poverty and Disadvantage among Prisoners' Families, Joseph Rowntree Foundation 2007](#)].
- Prisoners' families also experience health disadvantages including high rates of depression, physical illness, housing disruption and, for families of foreign national prisoners, permanent separation after deportation. [Source: [Poverty and Disadvantage among Prisoners' Families, Joseph Rowntree Foundation 2007](#)].
- The importance of family relationships is widely recognised in terms of reducing reoffending and preventing intergenerational crime.
- Families' access to health services may be affected due to imprisonment/conviction of a family member - this could be because they have had to move out of their home, or relocate.
- Families travel on average 60 miles each way to visit their relative in prison. It can be a very time consuming and costly as well as emotionally and physically challenging.
- Families of young offenders are likely to have a lot further to travel to visit due to the small number of young offender institutes.
- Prisoners disproportionately experience poor mental and physical health. Families and carers can help offenders access and maintain appropriate health support in prison and post-release in the community. However, the impact of imprisonment often results in poor mental and physical health outcomes for the families of prisoners.

Core principles:

- Families and carers are key advocates for prisoners, particularly prisoners who are vulnerable and have difficulty articulating their health needs. Families may also be key in supporting an offender/prisoner's health needs on release/probation but they often report not being consulted or informed about their relative's needs or care while they are in contact with the criminal justice system.
- Family members and carers should always be included and engaged with during any consultation process.

OFFICIAL

- Some families may not want to engage with services due to worries about stigma or confidentiality, or may not want people to know they have a relative in prison so any engagement activities should be sensitive to this
- The Care Act 2014 makes provision in relation to families and carers as well as prisoners. Families and carers should be included as part of the assessment of the health and social care needs of prisoners requiring services. Carers are also entitled to an assessment of their own needs.
- Confidentiality remains vital, however practitioners can explore 'floating' consent with prisoners which enables specific issues to be disclosed to families.
- There is a growing number of older prisoners so engaging with family/carers where there are dementia issues is important (see top tips for engaging with older offenders).
- There may be anxiety on how to support their family member's health issues (such as drug or alcohol dependence) on release and families often need support with these issues.
- Families' and carers' own mental and physical health needs must be acknowledged and addressed.
- There can be a barrier of mistrust to engagement that exists between families/carers and prison/healthcare staff. Participation activities should be aware of this.

Practical tips:

1. Contact voluntary sector organisations who work with offenders' families to help facilitate engagement with them. You can find a list of such organisations on the [Clinks' Directory of Offender Services](#).
2. Prison visitors' centres, also often run by voluntary sector organisations, are an ideal place to reach people visiting a family member in prison.
3. Families often travel many miles to visit their family member in prison and have to plan this in advance, so any engagement activity linked to family visits also needs to consider an appropriate timescale.
4. Voluntary sector organisations supporting prisoner and offender families may already have engagement networks in place.
5. Families may have limited time for engagement - relatives are often not resident in the area where their family member is in prison so face to face or regular engagement may be difficult. Planning engagement activities with families/carers in advance or using other approaches can be helpful, especially if the custodial setting is far from their home.
6. 26% of the prison population are from BAME groups so engagement with families/carers needs to take this into account and be aware of cultural sensitivities and any health inequalities.
7. Liaise with prisons to ensure that there is up-to-date information in prison visit halls about healthcare services and who families can contact if they have a concern.
8. Commission training to raise health professionals' awareness of the impact of imprisonment on children and families.
9. Some prisons have family group meetings which could be a possible avenue for engagement around health issues.

10. Circulate the free resources for health professionals about the children of prisoners from the [i-Hop website](#).

Case study

Nepacs is a charity based in north east England supporting the children and families of prisoners. This includes running visitors' centres, projects for children and young people, delivering training and a holiday scheme. The [Visitors Voice Project](#) offers families and other visitors an opportunity to feedback their experiences of prison visits to governors and service providers. Nepacs organise an annual event for families visiting prisoners across the north east. The head of commissioning, health and justice for Cumbria and North East, attended the 2016 event to speak to and hear from family members. She provided updates on the prison smoking ban, care of older prisoners and new psychoactive substances and was able to answer families' concerns about GP registration and the differing practice around prescribing anti-depressants in prisons.

Want to learn more?

[National Offenders' Families Helpline](#)

[PACT](#) – prison advice

[POPS](#) – partners of prisoners

D11. Service users in Mother and Baby Units

Context:

There are six Mother and Baby Units (MBUs) in England and Wales. They provide a secure setting for women subject to imprisonment to be detained while pregnant, or for their babies to remain with them up to 18 months old. In total these MBUs have capacity for up to 64 babies; and in 2015, 100 babies spent time in an MBU.

Core principles:

- As in all settings, women in Mother and Baby Units have a right to be involved in their healthcare and have a say in shaping and improving the healthcare services they receive.
- Pregnancy and the period after giving birth is a time of high anxiety for many women, and this can be especially true for those staying in an MBU. Participation activities should be run with sensitivity and take account of this.
- Women in MBUs may feel a level of suspicion towards those they view to be in authority or to be from 'official' services. However, this is not always the case, and it should not be assumed that current service users will be reluctant to share their views.
- Due to the small numbers of women in MBUs, individual experiences may easily skew the overall results when gathering feedback. Care should be taken to engage as broad a range of service users as possible.
- Family members and carers should also be considered as part of the engagement activity.

Practical tips:

1. Women in MBUs are subject to many of the same restrictions as those in prison, including receiving payments, access to computers and digital engagement – please see top tips to consider for prisons for more information.
2. Collaborate with voluntary sector organisations working with women in MBUs, such as Birth Companions or Barnardo's, to mediate the relationship with service users and overcome any mistrust. Birth Companions has a specific remit to facilitate the input of patients/service-users into consultations that include perinatal women in justice settings.
3. Using peer researchers to consult with current service users can be a valuable and cost-effective way to gather honest feedback.
4. Consult with (recent) former service users as well as those currently staying in an MBU to increase the potential numbers of women involved and provide a wider perspective. Again, voluntary sector organisations that work in the community as well as in the MBU may be able to assist with contacting women who have been released.

Want to learn more?

O'Keefe and Dixon (2015) - [Enhancing care for childbearing women in prison](#)

NSPCC/Barnardo's (2014) - [All babies count](#)

[Birth Companions](#) has a [Birth Charter for women in prisons in England and Wales](#)

E Involving people in procurement

Case study – Embedding Patient Voice in the West Yorkshire Prisons Procurement Project

Background to the project

NHS England has direct commissioning responsibility for healthcare for people detained in prisons and prescribed places of detention, which for this project includes a high security prison, two adult male prisons, two female prisons, a young offenders' institution (YOI) and a secure children's home (SCH). Historically, these services were commissioned by primary care trusts for prisons in their locality. As a result a range of different commissioning and contracting models were inherited. This procurement represents a critical milestone in the overall strategy to correct this.

Historically it has been challenging to fully embed the patient voice into health and justice commissioning due to the access issues with service users. Therefore, for this project, the Health and Justice team saw this as an opportunity to improve patient engagement, to ensure it was a central part of the procurement process and to deliver against the [NHS England Patient and Public Participation Policy \(2015\)](#).

What did we do and when?

Pre -procurement

- The NHS England Health and Justice Team conducted an initial patient engagement workshop with local criminal justice providers and stakeholders to understand how the organisation can better access the patient voice across prison settings.
- NHS England conducted a systematic review of already existing PPP mechanisms across Yorkshire and Humber, which have fed into public domain reports for each of the institutions affected by the procurement e.g. NOMs prison service level agreements, Independent Monitoring Board Reports and Prison Inspection Reports.
- An Equality Impact Assessment was carried out to ensure that any equality and diversity issues were considered when accessing the patient group.
- The West Yorkshire procurement project then outlined a communications plan. It defined the key patient groups and how they will be communicated with (and when) – considering factors such as access issues (to those 'in prison' and those 'experts in the community'), literacy issues and impartiality.
- NHS England then sought advice on accessing the patient voice from a partnership of organisations (lead organisation: [DISC](#)) who are experienced in involving 'experts by experience' in coproduction and as peer mentors. A clear service level agreement was set up around roles and responsibilities for all organisations involved.

Mid-procurement

- The team delivered 'targeted' patient workshops at all seven institutions affected by the procurement on behalf of NHS England, when possible,

OFFICIAL

without the presence of the establishment healthcare staff in order that patients can speak openly and with impartiality.

- The team established a clear audit trail identifying where patient feedback from workshops impacted on the procurement including specification design, bid evaluation question design, presentation question design and health service model (patient voice work stream was an ongoing agenda item at project board meetings).
- In collaboration with partners, the team expanded the bid evaluation project team to include an expert for each procurement lot:
 - A male expert by experience to work on the lot one (male high security prisons) and lot two (male adult prisons).
 - A female expert by experience to work on lot two (female estate).
 - Two young people (from Wakefield Youth Offending Service) to work on lot four (young person's estate).
- The team decided to ask a specific question to providers around their approach to engaging with the patient – to be evaluated and scored by the experts by experience (alongside prison governors as peer evaluators).

Post procurement

- Lessons learnt session conducted with those involved in the procurement process.
- The team will deliver a second series of workshops (in the affected establishments) to ensure that the patients are given feedback with a focus on outcomes of the initial feedback e.g. 'you said and we did'.
- During the contract mobilisation process the commissioners will ensure that the promises made around patient engagement as part of the bid submissions by providers are upheld and added to the NHS standard contract.

Project benefits of the embedded patient voice approach

- In line with the [Five Year Forward View](#) objectives this process is helping to 'break down the barriers' between patients and professionals. It supports the agenda of 'patients will gain far greater control of their own care' and also allows the health and justice team to 'become better partners with voluntary organisations and local community'.
- There has been a clear impact on project outputs such as scoring of the bid evaluations, specification design and healthcare model discussions – which were specific to the demographic of each procurement lot.
- The process encouraged the project team to challenge their personal professional perspectives on the value the patient voice can add to the procurement process.
- There were clear benefits for the 'experts by experience' who fed back that the process was 'empowering', 'confidence building', 'interesting' and enjoyable'. They also felt that their role had 'made a difference'.
- The viewpoints of the experts with 'lived experience' really pushed the bid evaluation panel to consider alternative viewpoints e.g. for lot four around young people, the experts pushed for increased consideration of the role of the 'family unit' surrounding patients rather than just individual patients.

OFFICIAL

- The team was able to communicate the 'experts' feedback from bid evaluation process directly to providers using the procurement portal - this ensured the experts saw how their inputs were used.
- Working with partner organisations to access the patient voice has added an extra dimension which has encouraged commissioners to think about how to engage with experts and service users in wider commissioning and other work streams.
- This process allowed the project team to develop a fit for purpose service level agreement between all parties and a procurement training pack for experts, which can be used in future work with experts.

Challenges of the embedded patient voice approach

- Due to the nature of the service users it was challenging to facilitate workshops and consultations in prisons (in particular access issues in high security prison).
- There was nervousness from professionals (and the service users involved) around how much value this process would add to the procurement which was thoroughly debated amongst the project team.
- There was a fear from partner organisations that the process would not be fully embedded and potentially tokenistic which again was thoroughly debated.
- There were fears from the project team that the 'service user experts' may not be ready to be involved in such a complex process (there were huge misconceptions around abilities of service users i.e. IT and literacy skills which was challenged by partners who provided support and governance).
- The process can be time consuming (for example requirement for lots of agencies having to liaise together regularly) but in terms of 'adding value' this was immeasurable.
- There were some difficulties in engaging young people as a group of experts. This process was eventually supported by a Youth Offending Service which helped support access to young people.
- Changes in project timescales resulted in losing an expert due to new timescales (common in procurements). To help avoid this from happening in the future, the team will consider using a bank of experts who they can tap into over a long term project.

What would we do differently?

- Be braver - involve the experts by experience in even more work streams of the project (e.g. presentation evaluation, running their own consultations/workshops, bid question design, reviewing specifications etc).
- Try to engage experts from more of a diverse minority ethnic background.
- Minimal jargon from other professionals (train professionals how to work with experts around transparency rather than just training the experts).

F Involving patients and the public in quality assurance

Context:

The quality assurance (QA) of services is an important part of understanding what is working well and what could be improved. Service user involvement in quality assurance should be embedded within the QA process.

Core principles:

- Involving service users in the quality assurance processes for service reviews brings a peer led and validated approach to looking at assurance.
- Service users bring a range of valuable insights to quality assurance processes. They often have direct knowledge of services, or recent lived experience and they bring a different perspective on what improvements should be prioritised.
- Service users often look at quality issues from a more holistic perspective than commissioners and clinicians. The patient safety and clinical outcomes are important. However, the patient experience as a whole and how this supports wider wellbeing and integration along a patient pathway can be drawn into sharper focus from service user involvement.
- Involving patients in the monitoring and assurance of services supports a cycle of continuous involvement, not just at the service planning stage.

Practical tips:

1. Use anonymised feedback and questionnaires; delivered in a way that meets the needs of services users (consider literacy levels, access to IT etc.).
2. Consider working with service users with recent lived experience to feedback in more details, for example focus groups.
3. Consider involving service users in contract management meetings.
4. Establish a schedule for regular quality assurance visits across all of the commissioned services. These could be announced or unannounced, depending on the nature of the service.
5. Include service users in the quality assurance team and their work. This might include training and supporting service users to review and query quality dashboards, or to become mystery shoppers, or peer researchers, or be a core part of the regular schedule quality assurance visits.
6. Consider developing Commissioning for Quality and Innovation measures (CQUINs) focused on service user experience that can be tested during the assurance processes.

G Useful lines of enquiry to follow up with providers

- 1) Does your local service development plan draw on existing sources of patient insight? For example health peer mentor schemes, monitoring quality prisoner life survey, patient engagement feedback from HMIP, CQC, Health Needs Assessment reports?
- 2) How are you actively engaging with and listening to patients and their families?
- 3) How are patients and their families involved in decision making?
- 4) Have the lead responsibilities and an approach for developing participation in the service improvement process been identified within the service provision?
- 5) How is participation aligned to the governance arrangements? i.e. does it feature in your senior management team meetings and/or prison partnership meetings with governors?
- 6) How are the voluntary, community and social enterprise sectors involved in supporting participation?
- 7) What impact has there been from patient and public participation? I.e. any changes to service delivery, models of delivery, staffing structures etc.
- 8) Has the feedback loop been closed? For example, have providers provided feedback to service users about the difference that their participation has made (a “you said.... we did.....” approach)?
- 9) Do you use the patient voice in your staff recruitment process? For example, are patients helping to design interview questions and/or interviewing new staff?
- 10) Are patients involved in health promotion, such as peer mentor schemes or health promotion champion schemes?
- 11) Have you used or do you propose to use any patient feedback in the local Health and Justice CQUIN schemes?

Glossary and Additional Resources

Glossaries

[NHS England's Statement of Arrangements and Guidance on Patient and Participation](#) contains a glossary on page 47.

NHS Confederation has produced an [acronym buster](#).

Additional resources

NHS England's commissioning intentions for Health and Justice Services 2016/17 are detailed here:

[NHS England's website](#)

[Clinks Guide to service user involvement](#)

[Clinks navigating the health landscape guide](#)

[The Academy for justice commissioning](#)

[The Power inside: the role of prison councils](#).

[Running a peer research project with offenders in the community. A handbook for staff](#).

[Improving your prisoner involvement systems: A toolkit for staff](#).

[Service user involvement with offenders in the community: A toolkit for staff](#).

NHS England (London) has a [patient and public participation programme](#), delivered jointly with Inspirit Training.

Acknowledgements

Thanks are due to the members of the development group (membership listed below) that co-produced this framework and have supported NHS England to test it during a six week engagement period with a wider audience. The engagement period included consultation with service users, frontline staff working with service users, voluntary sector organisations and NHS England commissioners and policy staff.

Thanks are also due to the many people who contributed to this work, and particularly to Ros Roughton (National Director of Commissioning), Kate Davies (Head of Armed Forces and their Families, Health and Justice and Sexual Assault Services), Christine Kelly (Assistant Head of Health and Justice), Caroline Twitchett, (Children and Young People Quality Lead, Health and Justice) and Andy Hunt (National Programme Manager Healthcare in Temporary Estate and Sexual Assault Referral Centres).

Working Group members:

Daniel Hutt, Chair	User Voice
Sally Brearley	Lay member, NHS London Health and Justice
Paula Harriott	Revolving Doors Agency
Dave Spurgeon	Nacro
Helen Dupays	Barnardo's
Leslie Dixon	Action for Prisoners and Offender's Families
Hazel Alcraft	Clinks
Philip Walker	The Survivor's Trust
Linda Lewis	The Survivor's Trust
Rachel Tonkin	Family Lives
Sophie Strachan	Health and Justice Clinical Reference Group (PPP member)
Peter Grime	NHS England (L&D team central)
Alice Williams	NHS England Patient and Public Participation team
Wayne Kirkham	NHS England Patient and Public Participation team
Rosie Ayub	NHS England Patient and Public Participation team
Nicola Seanor	NHS England Health and Justice North of England Commissioning Support
Hong Tan	NHS England Health and Justice (NHS London Commissioner)
Claire Weston	NHS England Health and Justice (East)
Andrea Collins	NHS England Communications and Engagement (South Central)
Arthur Ling	NHS England Health and Justice (Central team)

For further information about each organisation

- [The Survivors' Trust](#)
- [Action for Prisoners' Families](#)
- [Nacro](#)
- [Revolving Doors Agency](#)

OFFICIAL

- [CLiNKs](#)
- [User Voice](#)
- [Barnardo's](#)