Health and Care Experience Profiles: a qualitative research methodology for the integration index

What is the aim of the integration index?

The NHS in England wants to provide people with the best care possible. To do this it is important that hospitals, GP surgeries and community services, like physiotherapists, pharmacies, and mental health services always work well together.

These NHS services also must work well with local social care services, such as care homes and care provided in people's own homes, and public health teams, to ensure the help people receive supports all their needs.

This approach often requires the NHS and social care services to think about the role of other public services including things like housing, benefits, transport and education.

All these things play a vital role in supporting people's general wellbeing as well as their health. It is important to consider changing the way in which a service runs to better fit with other public services, such as public transport routes and timetables.

For the people receiving care it should feel like they are being supported by a single team which is considering all their needs and responding together as one.

How do we achieve this?

The NHS and social care services have been thinking about how to provide care in this way for some time, and important changes have been made already.

However, to know if these are working, they need to hear from people about their experiences of care. This is what the 'Integration Index' is all about.

The Integration Index is split into two parts:

- **The National index**
  A regular survey of people using the NHS which will ask the same questions of the same types of people in every area of the country. This will ask people whether they think services are working well together or not. It will help areas see how well they are doing compared to other parts of the country.
- **The Local index**
  A number of methods for local areas to gather more detailed views from people surveyed in the national index, or that are relevant to that town, city or county.

This will help the NHS and its local partners to understand how well services are working together for people who require it the most.

Health and care experience profiles

The health and care experience profiles project being led by Healthwatch is one of the local methods being developed to help the NHS and social care services understand how well services are working together from the perspective of people who need them the most.

This means that if the integration of services is successful for the people who would benefit most from joined up care and are frequent users of NHS and social care services, then lots of other people would benefit as well.

This method has previously been tested in five parts of the country, with five groups of people who have lots of interactions with NHS services, care support and other public or charity services. These five groups, or health and care experience profiles, were:

- Children and young people with mental health support needs who are becoming adults
- People with diabetes who are of South Asian origin
- People with learning disabilities and their unpaid/family carer, with a recent experience of hospital discharge
- Black men with a number of health needs including a recent experience of cancer
- Women with a number of health needs including a recent experience of a heart condition

For the purposes of developing this methodology, Healthwatch England had previously looked at all the national level user experience data held on each of the groups and looked at the policies[1] which set out what sort of care these people should be getting. Local Healthwatch have done the same in their area, looking at local data and policies. This will help local NHS and social care leaders understand how well they are doing compared to the national picture. Reviewing national and local policies and insight should be completed in one single step.

Local Healthwatch spoke to a small number of people from these groups and asked them to talk about their experiences of care. People were also asked about their

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[1] What is meant by “policies” – official documentation and publications that set out the expectation of care through examples of good practice and standards of care (e.g. NICE Guidance).

ideas for improvement, which the NHS and social care services are expected to use to make changes wherever possible.

The underlying principles of this methodology can now be used by the NHS and its partners to find out how any group of people might be experiencing care across different services. The Local Healthwatch network across the country is perfectly placed to act as a local delivery partner and can be commissioned to help carry out this work.

Benefits of using this methodology

The insight gathered will build an understanding of the differences people from a wide range of backgrounds and health and care needs expect, experience and want from the health and care services.

As a result, this will also be a mechanism through which better insight can be drawn on health inequalities and how to address them. The health and care experience profiles will have a utility beyond the immediate target groups, further improving the way that all services work together. For example, utilising a health and care experience profile for one group of people and improving their experience as a result of the testing, can improve experiences for other groups of people as well. Particularly, as making improvements in one health area or service will enable teams to work together in ways that will benefit other health area or services as well.

Using qualitative research methods, including literature reviews and focus groups or interviews, leads to more in-depth and detailed findings. It is particularly useful to further expand on why people feel a certain way and can introduce new topic areas that haven’t been considered previously. Therefore, this qualitative method is best used for explaining why things are occurring and what exactly can be done to address them. It is important to understand that a large volume of responses that may be statistically representative does not guarantee meaningful information, this is known as qualitative data saturation.

Who will do this work?

This methodology will be conducted on a local level to evaluate the progress of system-wide service integration and to better understand roles in the delivery of services.

Senior NHS and social care leaders

Senior NHS and social care leaders have a role to play in understanding how this methodology and insight can be used to help them develop a deeper understanding of key groups of service-users, when it may be appropriate to implement it to help support local improvement.

NHS and Social Care Engagement and/or Policy managers

NHS Engagement and Policy leads will be able to use this methodology in practice to help them to understand the system's progress towards service integration from the perspective of the people using the services.

Healthwatch

Healthwatch across the country can also implement and apply this methodology to evaluate their local systems and support their role as system delivery partners.

At what stage of service delivery is this work needed?

This work will have a benefit during all stages of service delivery. This includes conducting work:

- To specifically shape a service redesign project
- To design a specific solution to a problem
- As part of an evaluation of existing changes to assess progress
- As part of regular intelligence gathering and self-assessment for quality improvement purposes

This work may not produce changes overnight, and so it is important to monitor this over time. This could be in the form of following the patients who take part in this work or indeed following up with system partners to see how the findings are used. This should be considered when creating timelines and allocating the necessary resources for the development of a health and care experience profile.

Identifying health and care experience profiles

Identifying the health and care experience profiles is the first step in this evaluation. This is so that evaluators can prioritise and recognise groups of people who would most benefit from improvements to service integration.

This work should be conducted in collaboration with other organisations. Local Healthwatch would be useful in this instance as they have the capacity and relevant skills to carry out this work. However, Local Healthwatch will need co-operation from the system as well.

How to identify health and care experience profiles

To do this:

- **Familiarise yourself with the national level priorities and policies (e.g. NHS Long Term Plan)**

- **Conduct desk research to collect a list of topics and priorities in your local area. Using resources including:**
    - local implementation plans to identify populations groups and characteristics
    - Workplans for the coming financial years and previous
    - Healthwatch reports and insight
    - Local health inequalities data (e.g. PHE Health Inequalities Dashboard, NHSE Right Care Equality and Health Inequalities Packs)
- **Your health and care experience profiles will need to be refined and detailed.** Identify target groups and characteristics who will have the most interaction with and use of different services.

For example:

Children and young people's mental health has been identified as a priority in the NHS Long Term Plan. However, this target group is at risk of being too broad and vague, thus yielding less useful and actionable information.

Therefore, we would recommend you identify further factors which may influence service integration related to this group of people. This could include the assessing children's experiences of transition to adult mental health services.

- **Speak to stakeholders who could advise on priorities.**
  You can use this to gather more information if there are gaps in existing knowledge to set priorities. You should note who your consultations are with so that you can continue communication throughout the evaluation, secure influence and report interest to system leaders. Stakeholder engagement is particularly important to promote co-production, regular reporting and flagging any safeguarding issues.

  For example:
    - Advisory groups
    - NHS Trusts
    - Local councils or authorities
    - Local Healthwatch
    - Primary Care Networks (PCNs)
    - Patient Participation Groups
    - Clinical Commissioners/Integrated Care Systems
    - System leaders
    - Charities (especially those focused on particular conditions)
    - Joint Quality Groups

  - Self-advocacy groups
  - Service inspectors
  - Citizens panels
  - Contacts for other sectors, such as schools, voluntary organisations

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Top tip: Stakeholder Audit

It is advisable to conduct a stakeholder audit in which you record the process you went through to consult with stakeholders and identify who didn't engage so that you can escalate any issues.

Reviewing national and local policies and insight should be completed in a single step. Take a look at examples of the health and care experience profiles developed and piloted by local Healthwatch on the National Reports Library.

Developing health and care experience profiles

Creating and developing health and care experience profiles will enable evaluators to build a picture of what people are to expect from care using local policy and guidance, whilst comparing this to what people experience based on the most up-to-date insight.

How to develop health and care experience profiles

Once you have identified your core groups, you can begin to draft the health and care experience profiles using multiple sources of information relating to joined up working and integration of people's needs and service delivery.

The structure of the health and care experience profiles should include:

- **What are the characteristics of this health and care experience profile?** – Outline a brief description of the health and care experience profile (e.g. A young person with a mental health condition(s) who is transitioning or has recently transitioned from child and adolescent to adult mental health care services)
- **Rationale** – This is created based on the outcome of identifying health and care experience profiles and describes why integration would be important for this health and care experience profile.
- **What kind of care should this health and care experience profile be able to expect?**
  - **a)** Systematic search of online sources for relevant national-level policies/guidance. For example:
    - NICE guidance
    - SCIE

    - NHS England
    - Any professional bodies or other national organisations relevant to the health and care experience profile/characteristics

  b) Systematic search of online sources for relevant local-level policies/guidance. For example:
    - Joint Strategic Needs Assessments/Joint Health and Wellbeing Strategies
    - NHS Trust policies
    - CCG/Commissioning bodies policies or guidance
    - ICS plans
    - Health Partnerships/Partnership action plans (e.g. Learning Disability Partnership Boards)
    - Local Long Term Plans

      To note: it is important to be clear when a pathway policy/document is still in development and not fully implemented. i.e. an aspirational local diabetes pathway.

- **What does the existing user evidence tell us about experiences of integrated care for this health and care experience profile?**

  Insight should ideally be no older than three years to ensure relevance to the current context.

  a) Search of existing Healthwatch insight:
    - National Reports Library
    - Long Term Plan 2019 engagement

  b) Systematic search of existing relevant national insight. For example:
    - CQC reports
    - Any professional bodies relevant to the health and care experience profile/characteristics
    - Any national charities relevant to the health and care experience profile/characteristics
    - NHS England (e.g. GP Patient Survey, Cancer Patient Experience Survey)[2]
    - NHS Digital
    - HQIP reports
    - Patient Experience Library
    - Pubmed (using keywords: integrat* care, plus any relevant to the health and care experience profile/characteristics. Looking for findings from the UK, with a recent publication date).

  c) Systematic search of existing relevant local insight. For example:
    - Local Healthwatch research

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[2] NHS England GP Patient Analysis Tool - It allows you to do cross-tabulation with further demographic disaggregation at CCG level or national level, to evaluate the experiences and certain health outcomes for specific cohorts (e.g. an ethnic group with a specific long-term condition).

  - CQC reports relating to local areas/services
  - CCG and Local Authority insight
  - Local professional body or charity research publications relevant to the health and care experience profile/characteristics
  - Patient Experience Library
  - Patient Participation Group insight

Testing health and care experience profiles

Testing health and care experience profiles in local areas will enable evaluators to gather first hand experiences of how well services are working together for people who require it the most. In doing so, gaps in care may be identified and plans to improve integrating health, social care and community services can be considered.

How to test health and care experience profiles

Draft health and care experience profiles will need to be tested with the target group using the most appropriate qualitative research method, to gather their experiences of care and ideas for improvement.

The type of qualitative research method you use will depend on the people who you wish to engage with for your health and care experience profiles.

You can use one or both of the following:

- **Focus groups**
  A group of deliberately selected people who participate in a facilitated discussion to obtain perceptions about a particular topic. The size of the focus groups is often dependent on the local population and representation of certain groups of people. However, an ideal number for each focus group would be between five-eight people. More than this could make it difficult for you to ensure everyone is able to make a contribution. Below four people could limit discussions and impact the quality of information.
- **1:1 interviews**
  Interviewer asks one person a series of questions on a topic or item of interest. This method may be chosen in the best interests of the cohorts and the research itself. For example, a 1:1 interview may be more appropriate when engaging with young people or when discussing sensitive issues.

It is important to understand that a large volume of responses that may be statistically representative does not guarantee meaningful information, this is known as qualitative data saturation.

You should create a topic guide prior to conducting focus groups/interviews. A topic guide will allow you to outline the keys issues and areas of questioning you want to explore during the qualitative interview or group discussion.

You must choose appropriate materials for your groups (e.g. providing materials in different languages, BSL, images), obtain informed consent, collect demographic information, and record sessions for transcription or write detailed notes during the discussions.

Recruitment of participants

The following suggestions can be used to support recruitment of participants to focus groups and/or interviews.

Identifying participants:

- Contact local GP surgeries to identify people who are likely to participate and fit the chosen characteristics
- Utilise contacts through community groups to help identify potential participants
- Contact PCN/CCG Community and Engagement Teams to support recruitment
- Use own mailing list and online social media platforms
- Work with Healthwatch volunteers (e.g. Patient Engagement volunteers) and contact Healthwatch committees/board members to flag with anyone they interact with and use their networks. This is particularly useful if your board members are from a range of backgrounds with a diverse set of demographic characteristics
- Identify and contact online or in-person peer groups e.g., Diabetes UK south Asian group

Creating materials:

- Draft a participant information pack and consider different communication needs for your groups.
- Draft flyers to send out to patient groups. Contact with these patient groups will need to be made through NHS Trusts to mitigate data protection issues.

Promoting activities:

- Use online promotion with social media channels
- Work with CCGs to point people in the direction of information webinars
- Utilise a time slot at local system meetings (e.g. Children & Young People and All ages Mental Health Coproduction Collaborative Boards) Consider clear messaging of what you want attendees to do and the audience you are presenting to

Special considerations:

- Recruit appropriate facilitators. For example, Local Healthwatch representatives or finding community members who represent those you want to engage with

- Consider communication methods that people are most comfortable with. Offering alternative options other than online methods (e.g. phone calls) can enable people who are more digitally excluded to take part and feel more comfortable in a 1:1 setting

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Example:

If there is a certain stigma attached to the act of seeking help for specific health conditions, some people may be more comfortable in a 1:1 setting rather than a group.

Consider cultural barriers, such as some young people being uncomfortable being asked to engage directly as their community leaders or elders speak on behalf of their communities. This means that communication and engagement methods should be tailored to such an audience

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- Engagement fatigue could be mitigated by preparing to explain the benefits of the project and what participants will gain from this. Closing the feedback loop is imperative to ensure effective engagement. To address this, consider following up with participants over time.
- Consider geography of your area. For example, your area may involve two integrated systems within which you will need to recruit from.

Data Protection

A formal GDPR data sharing agreement is not necessary to get in contact with potential participants. This is due to the collaborative nature of this work that will allow stakeholders and partners to contact potential partners on your behalf.

Common themes relating to integration:

1) Communication: Communication and coordination between professionals. The system shares information through service-users rather than between services. This also makes it difficult to coordinate transitions between services.
2) Lack of information: Professionals not having the information they need to treat those in front of them.

3) Lack of continuity of care: Service-users having to repeat their story unnecessarily to different professionals. Service-users also having to repeat steps on a care pathway, such as diagnostics.

4) Lack of involvement: Service-users and their families not being involved in care and decision making.

5) Lack of holistic care pathways: Care pathways can sometimes not consider other needs and drivers of negative experiences.

6) Treatment burden: Service-users with multiple long-term conditions attending many appointments for which treatment is considered separately despite high comorbidity.

Presenting results

The information you collect from the testing the health and care experience profiles can then be used to support further development of the model health and care experience profiles. This information will be written into a final product (e.g. report, slide deck, presentation) that can be used as supporting evidence for service change.

How to present the results

Once you have developed your health and care experience profiles and tested them with the relevant groups, you can present your data/findings side-by-side with your health and care experience profiles.

The results of the testing phase should be written into a final product and an action plan be drawn up to address the gaps in care and where services can be improved. It is important to present the findings in a way that the system will be able to act on and help improve care that people receive. This means that you will be able to identify where integration has worked and where it may be lacking.

These results should then be incorporated in service delivery planning to improve the coordination of the health and care system based on qualitative indicators of integration.

To note: It is best to be transparent and aware of any limitations related to your research (e.g. small samples) and how this may affect conclusions and implementation of service changes. Being prepared to influence using your local relationships will be beneficial in supporting the use of this qualitative research.

Appendix

Each stage of the evaluation process will take a set amount of time to complete. Below is a sample timeline for how long each stage is anticipated to be:

		Week																										
Stage		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
Identify personas	Develop and agree initial criteria for identifying and selecting wellbeing personas	x	x	x	x	x																						
Develop personas	Analysis of data on each of the personas						x	x	x	x	x																	
	Collation of any policy documents that set out what each persona should expect from their care and useful insights from other data on current experience						x	x	x	x	x																	
	Draft one persona and sign-off broad structure									x	x	x																

	Draft remaining personas if necessary												x	x	x													
Test personas	Focus group recruitment															x	x	x	x									
	Focus groups in field																			x	x	x	x					
Present results	Findings of focus groups reported																						x	x				
	End of program report written up and submitted																								x	x	x	x