Health Innovation
Yorkshire & Humber

Driving Innovation Uptake Through Patient Insight

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Contents

Executive Summary

The effective and widespread introduction of innovations into routine practice across NHS care is an important strategy promoted by NHS England to improve health and wellbeing and reduce inequalities in patient outcomes.[1]

This project set out to understand how patient insight and experience could inform and accelerate innovation adoption, and how this approach could be transferred and applied to different innovations through a structured framework.

Based on five innovations that are part of the MedTech Funding Mandate (MTFM) and Rapid Uptake Product (RUP) programmes, real-world insight was gathered from patients with lived experiences of the innovations and the associated care pathways. Analysis highlighted three key themes that made the most positive difference to patients in the adoption of innovations:

- **Availability of support**
- **Communication and understanding about the innovation**
- **Understanding the impact of the innovation.**

The team applied these core themes to each stage of the patient's care journey and identified actions for the principal stakeholders involved in the adoption and spread of innovation.

A framework was developed by aligning what matters to patients with actions that key stakeholders can take at different points in the care journey. This framework includes seven high-impact actions that can be effectively applied to various healthcare innovations.

The framework embeds valuable insight and actions to support innovation project teams improve the spread of innovations, including greater collaboration between and co-production with stakeholders. Adopting this approach will enable more equitable spread and adoption locally, regionally, and nationally.

View the framework and high impact actions.

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[1] NHS Long Term Plan » Research and innovation to drive future outcomes improvement

Context

The adoption rate of innovations recommended by the National Institute of Health and Care Excellence (NICE) has often fallen short of expectations, despite the prevalence of various clinical conditions and NICE's forecast.

Accelerating adoption improves patient access to innovations and enhances health and wellbeing outcomes. Although some patient experience insights are incorporated during the design phase of new innovations, they are not widely collected and integrated into the spread and adoption plans for healthcare innovations. This means that these plans do not benefit from service users' insights and experiences and the additional value this brings.

This intelligence provides valuable insights into the benefits of innovations from a patient perspective and highlights the challenges patients face that need to be addressed to accelerate uptake. Understanding both negative and positive service user experience at scale brings important added value to enhance spread and adoption plans including:

- qualitative information that can enrich clinical and patient education resources
- a 'benefits narrative' to share with patient peers, creating a 'patient pull' for the innovation
- improvements in quality of life that have additional benefits (e.g. reduced side effects, reduced time off work, ease of use and therefore increased independence). This builds stronger evidence to enhance spread and adoption plans. It further enables these plans to create stronger alignment with other national strategies (e.g. prevention, personalised care, health closer to home) for greater leverage
- information that can help to shed light on reasons for low adoption and attrition rates. Poor patient experience of an innovation coupled with high clinical efficacy supports the identification of further work needed, e.g., around shared decision-making aids and improved education resources.

Without a clear understanding of how patients are accessing, experiencing, and using innovative treatments and pathways, there is a risk of exacerbating variation in patient accessibility and health inequalities.

The **NHS Accelerated Access Collaborative** (AAC) was formed in response to the 2016 **Accelerated Access Review**, with the ambition to help make the UK one of the most pro-innovation health systems in the world. The NHS AAC has identified the importance and value of patient experience and insight to enhance spread and adoption plans, improve clinical and patient education resources, create public awareness, and generate patient interest and desire to benefit from proven opportunities.

The Health Innovation Network (formerly known as the AHSN Network) is the innovation arm of the NHS and the collective voice of the 15 health innovation networks across England.

Health Innovation Yorkshire & Humber, a delivery partner to the AAC, has worked collaboratively with the **Yorkshire and Humber Applied Research Collaboration** to develop a methodology and framework to enable patient experience and insights to contribute to the adoption and spread of NICE-recommended innovation.

Aims, objectives and oversight

The aim of the project was to develop a practical framework for innovation project teams that facilitates the inclusion of patient and carer insights and experience into the planning and delivery of innovation spread and adoption programmes and projects.

This framework can be applied across health and care provision to enable all the principal stakeholders to collaborate more effectively around this core purpose.

A set of objectives defined the approach:

1. Understand current approaches to gathering and incorporating patient experience in spread and adoption planning, to inform key lines of enquiry in our study.
2. Collect patient experience from five diverse and recently introduced NICE recommended innovations to enable real world patient experience to guide and inform the building of the framework.
3. Commission an independent analysis of the patient experience findings to identify and theme priorities from a patient's perspective.
4. Combine the knowledge and experience collected to produce an evidence-based framework that will enable stakeholders to build and deliver more effectively the spread and adoption of proven (e.g. NICE-recommended) innovations across the NHS.
5. Produce a comprehensive report that describes the framework and how it was developed.

A steering group was established to oversee the processes and the development of the work, including an equal proportion of clinicians and managers, along with four patients who have diverse experiences and backgrounds. The steering group invited evaluators from the local Applied Research Collaboration (ARC) to review the delivery approach, and to independently analyse the data collection to minimise any risk of bias.

Approach

To ensure that the outcome of this work was robust and applicable to a wide range of innovations, the approach involved five important steps:

- Innovation selection
- Desktop review and gap analysis
- Patient interviews and data collection
- Thematic analysis
- Developing a framework from the findings

Innovation selection

Desktop review and gap analysis

Patient interviews and data collection

Thematic analysis

Developing a framework from the findings

Innovation selection

The five products listed below were selected to draw upon existing spread and adoption activity and offer an opportunity to gather data that can inform current plans. These products represent different types of innovation, different target patient groups, are used at different stages of a patient's journey and are at different stages of adoption.

This offered an opportunity to understand how a generically based framework could be transferrable across diverse innovations. Detailed information about the innovations can be found in Appendix A on page 28.

1. **Spectra Optia** (MTG28) – apheresis and cell collection platform for people with sickle cell disease who require automated red blood cell exchange.
2. **Asthma Biologics** – a group of medicines used by specialists to treat people with severe asthma. They provide a treatment option for people with severe asthma who continue to experience asthma symptoms despite taking usual treatments (including steroids).
3. **Four Benign Prostate Hyperplasia (BPH) Innovations** - technologies for alternative treatment to transurethral resection of the prostate (TURP) for benign prostatic hyperplasia:
   - **Greenlight** (MTG74) – uses a laser to reduce the size of an enlarged prostate.
   - **Rezum** (MTG49) – uses water vapour to destroy excess prostate tissue.
   - **Plasma System** (MTG53) – uses electrodes to cut out prostate tissue.
   - **UroLift** (MTG58) – lifts and holds the enlarged prostate tissue away from the urethra, relieving the compression of this organ.
4. **gammaCore** (MTG46) – a handheld device which alleviates the symptoms of severe cluster headaches by stimulating the vagus nerve.
5. **Placental growth factor-based testing (PlGF)** (DG23) – a blood test to diagnose pre-eclampsia in pregnancy (Triage PlGF test and the Elecsys immunoassay sFlt-1/PlGF ratio).

Desktop review and gap analysis

A wide variety of sources were used to understand what was known about current approaches to the collection and incorporation of patient experience into innovation development through to spread and adoption delivery.

Health Innovation Network National Product Leads for each of the five innovations were consulted to identify whether any patient insights had already been gathered relating to each of the chosen products. Patient groups and online forums were also explored to uncover opportunities for patient insights that could support and inform the spread and adoption of innovations.

A gap analysis identified unexplored opportunities for patient and public involvement and engagement. For each of the innovations, the relevant care pathways were reviewed to identify opportunities to include patients and their experiences throughout the patient journey. An example showing how the Benign Prostatic Hyperplasia pathway was reviewed can be found in Appendix B on page 38.

Findings from the gap analysis revealed common barriers to access specific innovations and included:

- Wide variation in knowledge and awareness amongst clinicians and patients, particularly in primary care.
- Availability of information and education on products and services.
- Travel to access products and services.
- Availability of innovations in local areas.

It also identified that patient feedback across all stages of the patient journey from presentation with symptoms, through treatment and onto aftercare, offers rich and valuable insights. This additional knowledge and understanding can be incorporated directly into the planning of activities and actions that will positively impact on the uptake and continued use of new innovations.

Patient interviews and data collection

A 'light touch' data collection approach was developed and tested, including interviews and engagement with patients with lived experience of the innovations. The findings of the gap analysis were used to develop an interview guide and key lines of enquiry aligned to seven stages of a patient's journey, outlined below.

Stages of the patient journey

The stages are described here in a sequence, however it should be noted that patients often revisit stages as new interventions are tried, their condition changes or further diagnoses are made.

Patients with previous lived experience or currently on the pathway for each of the five innovation products selected were interviewed. Interviewee recruitment involved a wide variety of approaches including use of social media, via clinical teams, patient groups and social support groups as well as referrals from others interested. A formal consent process clarified the purpose of the work for each interviewee, addressed individual access needs and communication preferences, reduced barriers to inclusion, and ensured that patient preferences were respected. An incentive was offered, in the form of a shopping voucher, as a small recognition for people's time.

29 interviews were completed during February and March 2023, with eight interviews conducted for PlGF, six each for the BPH Innovations and gammaCore, five for Spectra Optia and four for Asthma Biologics.

Stage 1 **Open and honest conversation regarding patient-led concerns or issue**

Stage 2 **Initial diagnosis and options discussed and understood**

Stage 3 **Expectations and potential issues clearly discussed, and treatment started**

Stage 4 **Patient experience on initial treatment shared and listened to**

Stage 5 **Alternative 'innovation' introduced based on shared decision – access and barriers resolved**

Stage 6 **Innovation reviewed to assess degree of patient satisfaction**

Stage 7 **Agreed decision on long-term care plans, patient feels hopeful about their future health**

Thematic analysis

The semi-structured interviews produced over 500 pages of rich insight. The analysis was undertaken by the NIHR Applied Research Collaboration Yorkshire and Humber (ARC). Interviews were prepared for thematic analysis using the six-step framework developed by Braun and Clarke.[2] [3] [4]

All interviews were audio recorded and transcribed. At this stage all transcripts were anonymised, personal information removed, data protection protocols were followed, and each was allocated a record number. The transcripts were then analysed by the ARC. Demographic data was not collected for this project and is identified as a potential area for further refinement of the framework.

The data were coded using an inductive (bottom up) approach to identify semantic themes with a realist perspective. This approach ensured a holistic analysis of the interviews, whilst capturing the diversity of opinions and views.

After the coding was completed by two analysts, the codes were combined and reviewed to identify themes and sub-themes. Themes were identified using Buetow's saliency criteria[5], which assesses the frequency (the recurrence of themes) and the importance of themes . Buetow defined importance as themes that "advance understanding or are useful in addressing" the proposed question. Frequency alone does not indicate importance, and an important theme may not recur often. Therefore, it is the analysts' interpretation of the data which determined which codes are and are not important.

Key patient experience elements were identified that could enhance spread and adoption planning.

Given the multiple stakeholders involved in the planning and delivery of innovative services, (including the technology developers, commissioners, healthcare professionals and patients and carers), it was explored how different stakeholders could make use of patient insight and experience intelligence. This enabled the framework to identify spread and adoption levers and be more effective for different users.

The analysis identified three themes and ten sub-themes (Figure 1). Additional information can be found on page 11.

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[2] Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2). pp. 77-101. ISSN 1478-0887 Available from: http://eprints.uwe.ac.uk/11735.

[3] Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. Psychologist, 26(2), 120-123.

[4] Clarke, V., & Braun, V. (2013). Thematic Analysis: A Practical Guide. Sage Publications Ltd: London

[5] Buetow, S. (2010). Thematic analysis and its reconceptualization as 'saliency analysis'. J Health Serv Res Policy, 15(2), pp.123-125.

Figure 1: Themes and sub-themes identified as priorities from patient interviews

Theme 1:
Availability of support

1.1 Inconsistency in support from healthcare professionals
1.2 Turning to other sources for support
1.3 Inaccessibility of treatment and innovations

Theme 2:
Communication and understanding information

2.1 Conflict between expert through lived experience and expert through professional experience
2.2 Provision and availability of information
2.3 Delegation of decision making

Theme 3:
Understanding the impact of innovations

3.1 Improved health and quality of life
3.2 Experience of using an innovation
3.3 A teaching and learning process
3.4 Wider changes to care pathways

The following section describes how patient experience data in each sub-theme was reviewed for key learning points, suggested actions and how these can enhance spread and adoption planning.

Note that the verbatim quotes featured are illustrative of patients’ perspectives. They are an indication of how patients experienced their health care interventions and how understanding these insights can enhance the adoption of innovations. Testing the accuracy of the specific activities described by patients was outside the scope of this report.

Theme 1

Availability of support

Theme 1: Availability of support

A theme that recurred was the variation in the availability of support both from healthcare professionals and other sources, including family and friends. A strong component of the theme was the impact on a patient's mental health derived from the lack of support, particularly around those suffering from cluster headaches (gammaCore).

Sub-theme 1.1: Inconsistency in support from healthcare professionals

Throughout their patient journey, but particularly in the early stages of diagnosis, participants reported the inconsistency in support provided by healthcare professionals. There was a reported lack of assistance available, both in the initial communication regarding the illness, treatment and the care provided post-treatment:

> "Well, there's been no follow up. I've just been sent home. 'Oh you're ok, carry on'."

Participants did not always identify the lack of support at the time. It was only on reflection that they realised the support they wanted, and frequently needed, was not there:

> "I was grateful that I was having the test and then beyond that I didn't really, sort of think about it. Now, after what I've been through, I think they should have taken that time with me. But yeah, it didn't happen."

This experience was not limited to one aspect of their healthcare journey, participants reflected on similar experiences in primary care and secondary care:

> "I wasn't passed on to anyone. And like my GPs couldn't get hold of anyone from the hospital to get me an appointment."
>
> "So, I didn't go back to the GP often because the lack of empathy, the lack of listening. But that's not every GP."

At times this left participants feeling somewhat abandoned by the healthcare system. However, this experience was not universal. Several participants mentioned the amazing support provided by healthcare staff, at all levels:

> "My doctor went back was also helpful because you know at the time, pre-eclampsia, obviously you will panic. But he helped talk...talk to me. And after his talk, I relaxed. So it was helpful."
>
> "I feel supported. I've got an asthma nurse that I can phone."

Sub-theme 1.1: Summary – What can be learned from this to support adoption and spread of innovation?

Participant accounts highlighted that there were gaps in how well-informed healthcare professionals were around these illnesses and related treatments. This highlights a need to address how they could be better supported to access this information. At the same time it is important that patients receive some information about their condition in a clear and accessible format. While most of these selected innovations sit within secondary care, the pathway starts in primary care, as reflected by our stages of patient journey on page 7. Therefore, it is important that both healthcare professionals and patients have access to this information as early as possible.

Actionable insights:

- **Creation of patient information resources:** innovators, suppliers, and NHS partners could all play a part in creating patient facing, accessible information for those potentially early in their care pathway or stages of patient journey.
- **Improve healthcare staff understanding:** innovators can look at how they can support healthcare professionals to build an understanding of a particular illness and their relevant treatments and where that may sit within a care pathway.
- **Information sharing:** Integrated Care Systems could continue to strengthen links between secondary and primary care providers so they can impart knowledge and share experiences of treating illnesses, overcome barriers that may exist and awareness of relevant innovations/solutions.

Sub-theme 1.2: Turning to others for support

At times participants reported reaching out to others for support. Who they turned to varied considerably, and this was based on the support network they had available. In the first instance it was family:

> “I think having this supporting family matters a lot.”
>
> “Luckily, I’ve got my family and my relatives here to keep me here. Otherwise, I wouldn’t be here.”

This support was predominantly emotional support, however some participants also noted that members of their family were in the medical profession, so they were able to get additional support via their family and friends:

> “I’m really fortunate. I have a sister-in-law who’s a paediatric registrar. And I have my brother-in-law [who] is training to be a GP.”

At times this included having friends use their contacts within hospitals to ensure the right level of support was available and provided in a timely manner:

> “I spoke to one of my friends. I sent him a message and just said I really don’t know what to do. I’m not sure what

> my next steps are. I kind of feel like I've kind of been abandoned and he just replied… he went to the medical director for the trust that I'm under and she reviewed my notes herself and found me a consultant to take me on".

More broadly, support was available through other channels, be it support groups on social media, and charities:

> "There's Facebook groups that have got me through it and that's part of the reason I want to do this today is to give back to that community that's helped."
>
> "A lot of this [support] was organised through Ouch UK".

This even extended to staff within companies of the innovations, who went above and beyond to help get the right type of support when it was urgently needed:

> "He [staff member at company] said I'm here for you no matter. Whenever you need me so we, we'd, WhatsApp and stuff like that and we should call and just have a catch up. When I couldn't get hold of the hospital I'd message and said, I can't get a hold of my doctor and he went. Don't worry, they're off sick. So, I'll forward you to get a new prescription card sent out."

Sub-theme 1.2: Summary – What can be learned from this to support adoption and spread of innovation?

Support networks are incredibly valuable to patients experiencing health issues and treatment.

Social media platforms and charities play a key role in offering support to those with ongoing health conditions, through speaking with others and seeking advice from those with a deeper experience or understanding of their condition.

Actionable insights:

- **Information signposting:** innovators should signpost patients to available support in relation to the condition the innovation supports – for example to Ouch UK for those who suffer with cluster headaches.
- **Involving local and national third sector organisations and groups:** healthcare providers can learn what support is available for their patients through discussion and signposting them to relevant charities if known.

Sub-theme 1.3: Inaccessibility of treatments and innovations

Participants reported the challenges they experienced when trying to access treatments and innovations for their conditions. This ranged from where patients lived for example living in a different NHS catchment area to cost centre for the treatment, through to the time taken to get a diagnosis:

> “It really does depend on where you go, doesn’t it?” “It really does, and that’s the problem with this post code lottery. But if it’s just a blood test, why can it not be one across all hospitals?” (PLGF)
>
> “I think for instance if [treatment A] cost £100 a month. Whereas [the innovation product] costs say £500, they’re going to go for the cheaper option all the time.”
>
> “But they just didn’t have the funding. There’s not a lot you can do unless you go private.”
>
> ”Special transport could have really made life easier, way easier, or maybe some form of reimbursement because you don’t want to. Thinking should I go for my exchange, or should I cancel because I haven’t enough money?”

In some cases, this resulted in considerable delays for participants, ranging from a few months to over five years, which in turn had considerable impact on their health and wellbeing:

> “Mental health goes through the floor. I think from the minute someone gets diagnosed, they need to be. It’s got to be so much quicker. I mean, five years. What? What was that? 2008 from 2013 to get proper help. It’s too long in my opinion.”

Sub-theme 1.3: Summary - What can be learned from this to support adoption and spread of innovation?

The innovations selected for study in this project have approval from NICE. The primary purpose of the MTFM and RUP policies is to support faster adoption and spread of proven innovations to patients, and improving equitable access. It is key that commissioners and providers engage with these policies, adopting clinically proven, cost-effective innovations so patients can benefit.

Actionable insights:

- **Review NICE guidance:** commissioners and providers can routinely review NICE guidance and understand where innovations may be most impactful for their services.
- **Support innovation rollout:** commissioners and providers can actively engage with national adoption and spread policies by leveraging the support of innovators and partners, including local health innovation networks, to effectively implement these life-changing innovations.
- **Project engagement:** such as considering Supply Chain’s Value Based Procurement which shifts the emphasis from a reduction in product costs to consider technologies that can influence a reduction in total costs along the patient pathway, thus enabling sustainable increased savings and improving patient outcomes.

Theme 2

Communication and understanding of information

Theme 2: Communication and understanding of information

The next theme identified by the data was around communication, both verbal and written, and how this affected the relationship between participants and healthcare professionals. As with the provision of support, there was considerable variation reported in the quality and quantity of communication, with participants generally preferring more information tailored to them, their situation, and their level of understanding:

> "I think being provided with more information could have helped a lot."
>
> "I don't want layman's terms tell me how it is and if I don't understand, I'll ask."

Sub-theme 2.1: Conflict between experts through lived experience and experts through professional experience

Part of the challenge around communication related to participants feeling that healthcare staff were dismissive of their views, with participants reporting that they were not listened to by healthcare professionals, despite repeatedly explaining their situation:

> "I felt I'm not listened to and even now talking to a neurologist, and I don't feel like I'm listened to... seems to fall on deaf ears."

Furthermore, it was noted that on occasion healthcare staff dismissed the participants' comments, which over time can have a negative impact:

> "Instead of helping me and diagnosing me, they said that I wasn't taking my medications properly, there was no coherence to the medication... I was devastated because actually, after a while, you begin to question yourself."
>
> "I think it started from the age of five. And it was constantly nauseous all the time, banging headache. And the doctors just go, oh, it's a migraine. You'll get over it. And so, for 30 years... after going to my doctor's repeatedly and just getting told oh do a food journal, cross out caffeine and don't take any painkillers whatsoever."

This may in part be due to a lack of prior knowledge or experience on the healthcare professionals' side, which was highlighted by participants:

> "My midwife... she didn't know about pre-eclampsia. In fact, when the doctor told me about it and I went to her, told her about it, and she was also surprised. 'Like, wait, what's pre-eclampsia?'"

> “The average person that suffers with cluster headaches. It does take around two years to be diagnosed with it because it’s not that much of a familiar condition… if I’ve been to A&E before, they’ll pop me in the head trauma. As if like I’ve been in a car crash or something. Like even just basic NHS staff aren’t familiar with the condition, you know. So, I think it does need a bit more awareness.”

One of the participants, a doctor, reported being unaware of the available treatments, emphasizing the importance of valuing patients’ perspectives as an expert in their condition through lived experience:

> “I’ve been a doctor for like over 10 years and I still didn’t know the treatment was available, do they know (in primary care)? And does everyone who’s got (it), I know some people don’t find out they’ve got sickle cells… for whatever reason they’ve managed to stay well, and do they know that they should be seen by a haematologist regularly?

As a result of their experiences, many participants reported having to be “a lot more proactive” with regards to their condition and to access the treatment and support they needed:

> “I felt a bit of a sort of fight to get it and it was only, I think, because of my history that it sort of happened regularly and that was because I asked regularly as well”

Sometimes this includes conducting additional research prior to appointments to prepare:

> “In my first pregnancy, I developed pre-eclampsia very severe, and we lost my daughter because it was misdiagnosed… I went into my second pregnancy a lot more informed.”
>
> “I then researched the condition, but I know at the time they didn’t do the BPH procedure. So when I went back to see him, I asked him if he could… transfer me to someone who could… carry out this procedure?”

Adopting this approach meant participants felt more “in control” of their situation:

> “If I hadn’t have done all then probably, I wouldn’t be in the position to have it because it was never mentioned by the consultant. It was mentioned by me.”

Sub-theme 2.1: Summary - What can be learned from this to support adoption and spread of innovation?

MedTech innovation aims to address a specific health need, therefore it is vitally important patients are listened to, with their needs acknowledged and understood. To do this, everyone involved in the care pathway needs to be adequately informed, whether that is in relation to understanding the patient’s health condition and how it’s impacting their quality of life, or suitable treatments available that they could benefit from.

Actionable insights:

- **Identify existing patient insights:** providers and commissioners can undertake a search of existing Patient and Public Involvement and Engagement (PPIE) research and activity, to understand patient commentary about real world experience and access to related innovations (e.g. improved quality of life).
- **Seek patient feedback:** suppliers, providers and commissioners can discover whether patients value the innovation. Do they feel it is right for them? Have they any concerns about using the innovation?

Sub-theme 2.2: Provision and availability of information

A common component mentioned throughout the interviews was the availability of verbal and written information pertaining to the treatment and innovation. Overall participants reported there was a general lack of information provided by healthcare professionals, which left many participants feeling uninformed about their condition and the available options:

> “Surely they’ve got, you know, a duty to the patient to give the patient all the information so they [the patient] can make an informed choice.”

This was partly down to the language used in conversations, and some participants struggled to understand what was trying to be communicated. Participants commented that having information prior to the appointment would be helpful, thus allowing the participant time to review and understand the literature, which was at times related to quite an emotional topic:

> “My partner and I have both been to university and are able to understand scientific information and it still wasn’t clear... people that sort of struggle with literacy skills and things I think it would be really hard.”
>
> “Maybe before an appointment it would be handy if a patient could be sent the literature to read before an appointment, so that when they go to an appointment, they are fully armed and they can have questions prepared in case their questions aren’t answered in the consultation.”

Inaccessible information often resulted in patients having to use other sources to understand their condition and what their treatment options were. For others, if alternative sources were not available this lack of information presented a challenge which affected their wellbeing:

> “I had to Google, look at the pre-eclampsia on Internet for me to really get what was going on with me.”
>
> “I kind of feel they didn’t give me enough. You know, when it comes to treatment information and everything, they didn’t give me an answer. You know, I almost slipped into depression because of this.”
>
> “When I had my first child, I had my normal bloods at 8 weeks and I got a phone call back saying that my PAPP-A level was low and that I needed three extra scans. But there’s no other explanation other than that.”

Conversely, there were instances of excellent communication and healthcare professionals checking the participants' understanding of the information they had been given:

> "She explained it to me, my special midwife, she was great. Yeah. She said, you know what this is for, what does it show, and she made a little diagram showing, you know, what happens with preeclampsia, the hormones when they get released and actually went through it with my husband as well."
>
> "I had an online consultation with an employee, and he works for, I'm not sure if it's [patient names two innovations]. So, he went through every training with me telling me how to use it."

In general, there was a balance that needed to be struck regarding the provision and availability of information, however this balance appeared to be very participant specific. Some participants wanted as much information as possible early on, ideally on paper, whereas others were worried about being given too much information to process:

> "It's one of them tricky ones, isn't it? If you get too much information at the beginning as a patient, they won't go through the stages of treatment and the escalations of intervention until they get the right one".

Overall, the analysis suggested participants wanted to have information on paper that they could read in their own time, but this should be supplemented by conversations with healthcare staff, who would go through all the information and check the patient's understanding:

> "If the doctors would have given me enough information like what I really need to know about pre-eclampsia, what is it? What is it cause? How can I prevent it? How can I tackle it? You know, it would have been better, but just dropping a bombshell on me like you know, you have the pre-eclampsia and not helping me."
>
> "She's a nurse, so when she went there, they talked to the doctor, and she came and explained things to me. I got the information from her."
>
> "No, I don't feel I did, even with all the reading I'd done. I'd come out of meetings with my consultant and when I'd gone back in for checks I'd be running things by her because it wasn't explained to me."

Sub-theme 2.2: Summary - What can be learned from this to support adoption and spread of innovation?

How, when and at what level information is communicated to patients was another key finding participants reflected on. Conflicting preferences emerged, which further demonstrates the need for innovators and providers to offer a range of information, provided in a variety of accessible ways to reflect the diverse communication needs of the population. The need for personalised care, treating each person as an individual and being empathetic to patient needs in providing useful information, was a common finding throughout the participants' comments.

The timing of when this information is made available was also raised. Providing patients and carers with information at the right time, providing it is understood, can help reduce delays in when the patient may receive treatment, which is clearly of benefit to the patient, but also to providers in reducing the need for further patient follow up and consultation.

Actionable insights:

- **Co-production:** suppliers, commissioners and providers could collectively facilitate patient focus groups to co-produce patient facing information. This includes determining what information is important to them, the level of information required, and decide how best to present this information i.e., leaflet, videos etc.
- **Information provision:** providers should review when information is provided to patients throughout care pathways to determine whether there are gaps. Can patients be provided with information prior to consultation with health care providers where an informed decision on treatment may be expected? Is there an opportunity to provide feedback following the treatment?
- **Explore additional information channels:** suppliers, commissioners and providers could signpost patients and carers to further information sources, such as those available through charity websites, forums, etc.

Sub-theme 2.3: Delegation of decision-making

The lack of patient understanding meant that, in a few cases during the patient's journey, they delegated decision-making to the healthcare professional. The reasons for this were multiple, either participant felt the healthcare professional knew better:

> "So when you're going to see a medical person you know, it is then their job to enlighten you so you know which path to take."

Or the participant did not fully understand:

> "I was kind of more being led by the medical team because I didn't really understand what was going on at the time, I think now I'm a little bit more proactive."

Or in some cases, participants felt they were not given any choice:

> "I'm not 100% certain whether I had an option. I think it was just, I was happy to just go along with anything that was said and due the nature of the headaches."
>
> "I think I had no option for me because I was not even enlightened to what it is and for me it was just only you're going to be fine, but we just have to run some tests on you. I was not enlightened with what is happening."

During the interviews a few participants reflected that perhaps they should have done more to question the approach taken or request specific actions to be taken, however at the time they felt that they were not able to do this:

> "I think sometimes you need to be completely led by the team that's looking after you. I do think like there are times where medical teams need to listen more to patients, but I also think there's times where actually our medical team does know best."
>
> "People [doctors] do not listen to you."

Sub-theme 2.3: Summary - What can be learned from this to support adoption and spread of innovation?

These patient comments demonstrate the need for good communication between patient and healthcare providers, underpinned with the appropriate information, to address gaps or understanding regarding a patient's condition, diagnosis, or treatment options. It is critically important that a patient is listened to and heard. As they start their patient journey, supportive information and open communication with healthcare professionals about their health condition(s) and possible treatment options will enable and foster better informed decision making.

Actionable insights:

- **Provide information at the right time:** provision of information to develop understanding at significant points, as directed by the patient along their care pathway, e.g. BPH treatment information such as those found in the British Association of Urology Surgeons once prostate symptoms have been diagnosed.
- **Give patients time to understand:** healthcare providers should determine whether they allow patients enough time to decide how best they proceed, which could be considering new information being received and understood.

Theme 3

Understanding the impact of innovations

Theme 3: Understanding the impact of innovations

The final theme relates to the impact of the innovation on the health and wellbeing of the participants. Given the project considered multiple innovations across five different conditions, the results are presented using common findings.

3.1: Improved health and quality of life

In relation to the treatment innovations, participants were asked if they felt the innovations had improved their health and or had life changing impacts:

> "It's improved my health, and my bloods, and how I feel" And "As soon as she got the cell exchange the next day, it was like a new lease of life." (Spectra Optia)
>
> "Not feeling pain was a brilliant feeling. So I could socialise. And go to work. I didn't have any time off whatsoever." (gammaCore)
>
> "It's changed my whole life around because of the benefits of the treatment" and "My life has completely changed." (Asthma Biologics)
>
> "And it stopped the catheters. And you know, this was in December, and you know it is completely, life changing. Absolutely, life changing." (BPH innovations)

However, the extent of the improvements was also varied and mixed. Patients interviewed demonstrated mixed experience, some stated procedures had a positive impact and changed their life, whereas others suggested it had worsened their condition:

> "I was in real discomfort for quite a long time after using it, and it did put me off using it again." (gammaCore)
>
> "I don't know if the operation was a success or not, but I've been left now worse than before my operation." (BPH Innovations)

From participants having had the PlGF testing, while not a direct treatment but a diagnostic test, the impact for patients in understanding whether they may have pre-eclampsia during their pregnancy was reassuring:

> "I've had a rough experience but looking back right now and I think it was best for me to get the test because I think I know what I'm suffering from. Like I knew what I'm suffering from, rather than I could have just stayed put and things got worse."
>
> "And I was having the second part of my scan and they were looking at all the different bits. Once they got all the information and said right, so we've got everything together. You're not at risk. So this is really positive. And that was really good to kind of leave on good news knowing that I'd have my daughter in like 3-4 weeks' time."

This was particularly impactful for one participant who had previously developed pre-eclampsia and not had the PlGF test, creating a deeper understanding of the condition, its tragic consequences, and the impact of the innovation:

> "In my first pregnancy, I developed pre-eclampsia very severely and we lost my daughter. I didn't have the predictive screening in that pregnancy. I went into my second pregnancy a lot more informed. I think it does give reassurance. It's sort of having that real concrete answer, and I think is a good thing and will save lives."

Sub-theme 3.1: Summary - What can be learned from this to support adoption and spread of innovation?

The positive or indeed negative impact of innovations on patients' health and wellbeing is important to consider. Having access to lived experience which describes the impact of an innovation helps to make informed decisions about its suitability and raise awareness in general about conditions which can support the adoption and spread.

Actionable insights:

- **Data collection:** ensure that the collection of data about the impact on patients is included in the evaluation planning.
- **Create an informed decision-making process:** enable planning and ongoing review of adoption and spread including the feedback from the patient (and carer) perspective.

3.2: Experience of using innovation

Participants commented on their experience of using the innovation or having it administered.

> "It just staggers me that it's not done more because it is so simple. You know, they took the blood in a few minutes and then it was back within two hours. And it gives you so much information." (PlGF)

Although some participants reported difficulty in adjusting to the treatment:

> "It's taken me a while because the thought of injecting yourself just doesn't seem natural to me." (Asthma Biologics)
>
> "I don't know if stimulating the vagus nerve aggravated it or something. I'm not too sure, but then once I've used it, it then brought an attack on. He [supplier employee] was like but you need to just try and persevere with it." (gammaCore)

Sub-theme 3.2: Summary - What can be learned from this to support adoption and spread of innovation?

The impact and influence on patient outcomes and healthcare provider experience of using an innovation should not be underestimated. The appeal and continued use of an innovation may be down to its user experience and equally may become unused if this experience is poor. It is also important that users understand whether there are any alternatives available if the innovation that they are currently using is not right for them.

Actionable insights:

- **Learning materials:** suppliers and innovators should invest adequate time to understand the patients' need for learning and training materials, developed through co-production so they are far more likely to be fit for purpose.
- **Potential for change in practice:** guidance, instruction, and training needs to be provided by the innovators to support patients and healthcare providers as well as an acknowledgment and understanding that a change in practice or a learning curve may be involved.

3.3: A Teaching and Learning Process

There was a shared view that many healthcare providers and patients need to be more familiar with how conditions present so the right treatment can be determined:

> "I didn't know that the exchange transfusions was a treatment until I was unwell and admitted to hospital and I'd been at that point, I've been a doctor for like over 10 years and I still didn't know the treatment was available, so I think you know lots of, you know, people in primary care. Do they know?" (Spectra Optia)
>
> "I was involved, but the level of involvement was also proportionate to their depth of knowledge about presentation of asthma." (Asthma Biologics)

There were also comments that patients who had the PLGF test felt they needed to do their own research around the condition and symptoms to learn more about pre-eclampsia:

> "I was very much aware, and I actually saw advice from Apex, the charity."
>
> "no one told me about preeclampsia. It was only me looking online, thinking about all my different symptoms that I had that I was starting to get there."

Sub-theme 3.3: Summary - What can be learned from this to support adoption and spread of innovation?

The findings show a need for more effective management of patient expectations in understanding health conditions and subsequent treatment success rates. There needs to be an acceptance that this may involve learning on the part of both the health care provider and patients.

Actionable insights:

- **Training and development:** the requirement for additional materials and information that can be used by clinicians and patients must be thoroughly researched and the findings actioned.

3.4: Wider changes to care pathways

There were several comments that referred to where the innovation sat within the care pathway, and whether it could be offered to patients earlier.

> "Get the gammaCore devices out early."
>
> "She [registrar] said she was going to speak to the consultant about putting me forward for biologics. And when I saw the consultant then, like 6 weeks later, that hadn't happened."

There were also comments concerning inconsistent aftercare for the BPH innovations with some patients experiencing complications, such as bleeding, and not being offered any post treatment medical help.

> “Even last week when they sent me home from the hospital, I was still losing a little bit of blood even after being in A&E. Well there’s been no follow-up. I’ve just been sent to home. ‘Oh you’re ok, carry on’. But I’m not.”
>
> “The discharge papers should have been enough. All I’ve got on the sheet is information after the event, mild bleeding for 48 hours. That’s really it. Well, I got severe bleeding after 72 hours. No follow up, on the sheet it says it’s a telephone conversation in three months’ time.”

Sub-theme 3.4: Summary - What can be learned from this to support adoption and spread of innovation?

This highlights the importance of care pathways being regularly reviewed, particularly when an innovation is introduced. When a medical innovation is adopted, it may create opportunities or a need to make wider care pathway changes.

Actionable insights:

- **Regular pathway review:** whatever the change or impact, the introduction of the innovation should prompt a review of the care pathway it features and/or others it may impact. This will also raise other crucial factors involved with care pathway changes, such as impacts on healthcare professionals involved within the pathway and the need to collaborate across primary and secondary care.

Using the findings to develop a framework

From the evidence gathered, it is clear that there is a need to address three specific patient-centred priority themes to effectively drive sustainable spread and adoption of innovation:

- Availability of support.
- Effective communication.
- Understanding the impact of an innovation.

All three must be addressed to enable the full potential of an innovation to be realised. Additionally, the data indicated that effectively addressing these themes would require actions from different stakeholders.

The team identified areas of responsibility and action for the following stakeholder groups:

- Patients.
- Innovators/suppliers.
- Service providers.
- NHS commissioners.

The team also used a simple seven-stage patient journey approach to structure the data collection and extract valuable intelligence.

This approach sets out a generalised framework that aims to connect three different dimensions:

- Priority themes identified by patients (support, communication and impact).
- Actions for different stakeholders involved in the adoption of innovations.
- Developing insight at the different stages of the patient journey.

Understanding patient experience and insights from each of these perspectives will result in increased understanding of opportunities for action to increase adoption. It will help to understand where there are patient-identified gaps that act as barriers to adoption. The result of applying this framework will be an action plan for all stakeholders involved in accelerating the spread of innovations at multiple ‘touch points’ of the patient journey.

The analysis also revealed that despite the difference in the type of innovations studied, there were many common patient-centred themes, suggesting that this approach highlights areas for action that are transferrable to many different innovations. The framework will therefore be a useful tool for innovators and other stakeholders working on the introduction of new and innovative products and services.

However, it is recognised that different innovations may require bespoke considerations in the context of the patient journey. For example, innovations more applicable to end-of-life care may need to gather data around the ongoing care stages of the patient journey. In contrast, innovations linked to screening and diagnostic testing are more likely to build on the earlier stages of the journey.

This means exercising judgement to prioritise different stages of the patient journey, focusing on those most suitable for a particular innovation.

Recommendations

Many barriers to the early adoption and spread of innovation are well known and include cultural, structural, and financial constraints. In the original proposal it was hypothesised that a systematic approach to collecting, understanding, measuring, and analysing patient experience should be applied to all innovations supported for national adoption to enable greater and equitable spread.

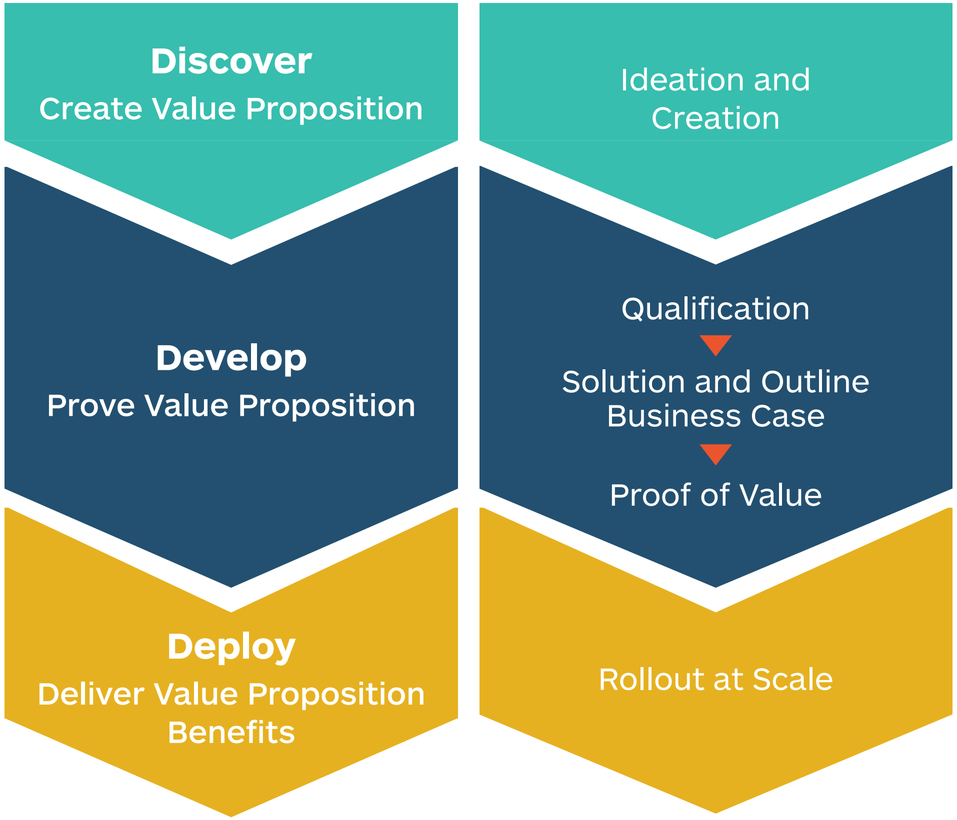
Key recommendations are summarised below:

1. Innovations should evidence continual and impactful collection of patient insight and experience from early-stage ideation through to spread plans at system level.
2. Adopt an evidence-based and structured approach to gather and review patient intelligence that will identify insight for different stakeholders to act on.
3. The use of patient experience and insight data should be embedded within current operational spread and adoption planning processes.

Suggestions for health innovation networks

All health innovation networks in England have a commercial team who support innovators with commercialisation and adoption, aligned to regional and national unmet NHS needs. Funded via the Office of Life Sciences, the commercial support offer comprises a ‘universal offer’ which includes support with product and technology development, evidence generation and adoption. This support can range from dedicated 1-1 support, innovation surgeries and signposting, to more intensive support such as accelerator programmes.

All health innovation networks support the framework below called the ‘innovation pipeline’. This is a visualised gradual process for developing, evaluating, and deploying innovations that address both local and national needs, supported by evidence, insights and analytics.



Discover
Create Value Proposition

Ideation and Creation

Develop
Prove Value Proposition

Qualification
▼
Solution and Outline Business Case
▼
Proof of Value

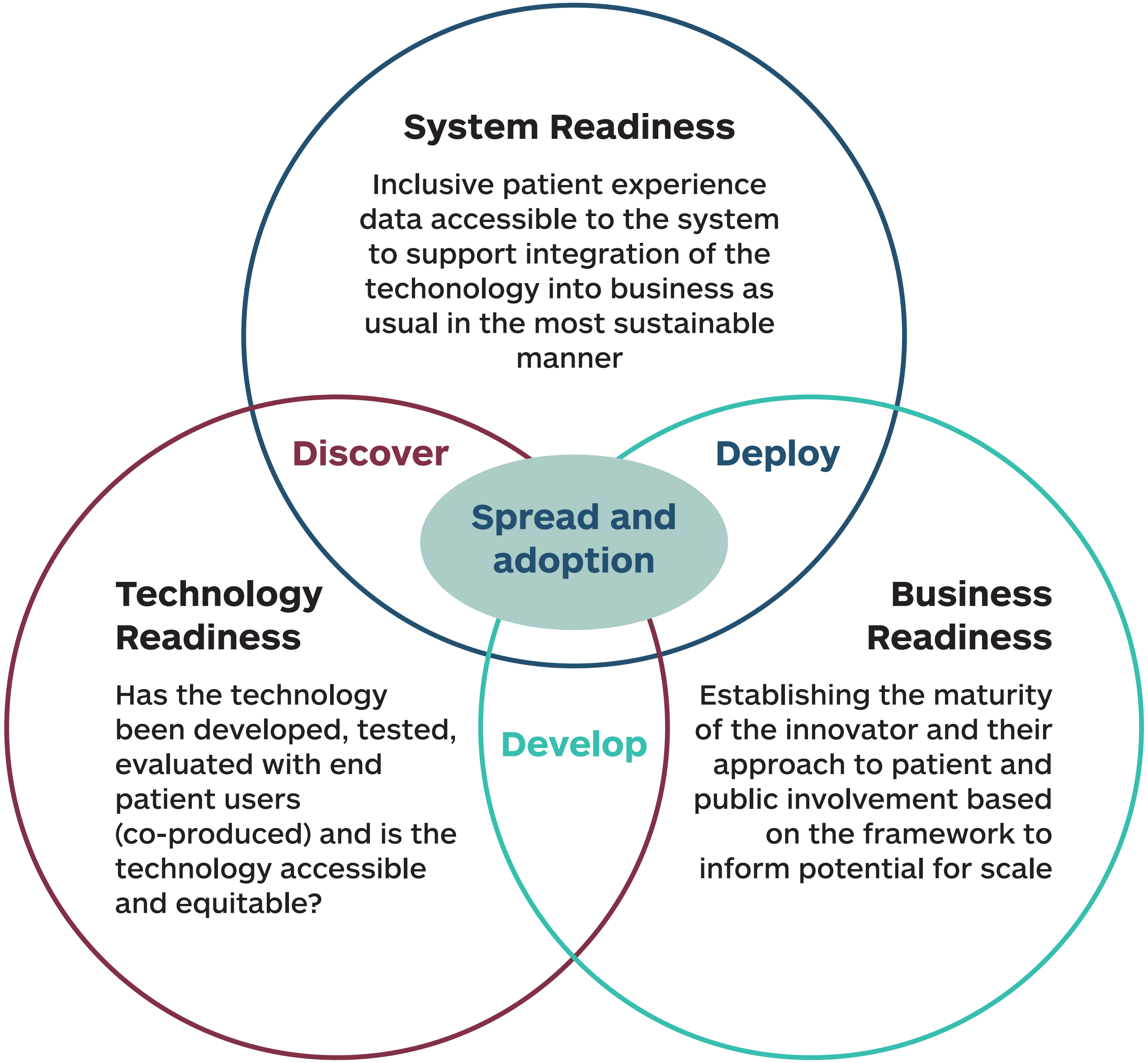
Deploy
Deliver Value Proposition Benefits

Rollout at Scale

Recommendations

Small and Medium Enterprises (SMEs) and entrepreneurs can be supported throughout their journey from early-stage ideation to minimum viable product (**Discover**) to support with real-world evaluation, value proposition, regulatory and business cases (**Develop**) and then complex spread and adoption support (**Deploy**) which may include procurement and commissioning at scale.

When considering the patient experience/insights framework, there are opportunities to test and embed this approach with innovators as they develop their technologies/services. Broadly speaking, patient insight and experience data can be seen as integral to adoption via the pipeline shown here:



System Readiness

Inclusive patient experience data accessible to the system to support integration of the techonology into business as usual in the most sustainable manner

Discover

Deploy

Spread and adoption

Technology Readiness

Has the technology been developed, tested, evaluated with end patient users (co-produced) and is the technology accessible and equitable?

Develop

Business Readiness

Establishing the maturity of the innovator and their approach to patient and public involvement based on the framework to inform potential for scale

Recommendations

Health innovation networks already ask many of these questions when engaging with innovators, and so this framework could support the future adoption of innovations which are able to demonstrate maturity against the framework. Health innovation networks' suggestions include:

- **Testing:** seek opportunities to test the framework principles with a selection of innovations supported via the innovation pipeline at all stages, including those without/outside of NICE approval.
- **Understand existing PPIE:** ask innovators some questions to understand where and how they have incorporated patient experience and associated data whilst developing their innovation. This should be aligned with questions around how and where innovations may narrow health inequalities and improve access.
- **Incorporate existing patient insights:** where robust patient experience/insight data is available, this should form part of adoption discussions with the NHS and care organisations and be considered and presented alongside other evidence such as clinical outcomes, efficacy, and value for money.
- **Map patient interactions:** Innovators should be encouraged to consider existing clinical or service pathways where their innovations might be used and map patient experience data collection 'touch points' to support the real-world evaluation of their technologies.
- **Utilise pilot/test bed PPIE:** where innovators are setting up pilots, then patient experience data from that trust/organisation should be collected as part of any evaluation.
- **Patient experience measures:** support innovators and adopting trusts to develop some clear measures to capture patient experience and insights. This feedback can be particularly useful where an innovation has the potential for wider adoption.

Suggestions for NHS England

- **Testing:** further testing of the application of this framework across wider innovations.
- **Explore variation:** explore the use of the framework to understand any variation in patient experience associated with nationally prioritised technologies.
- **New approaches:** support the development of approaches for collecting and sharing patient experience data between key stakeholders.
- **Support healthcare innovators:** explore the use of patient experience data as part of the National Innovation Service portal.

Recommendations

Suggestions for further development

This section sets out some ideas for further exploration, including how to take the framework forward:

- **Testing:** test the framework with a wider variety of innovations, bringing larger data sets from different types of innovations applicable to different segments of the patient journey to support enhancement of the framework.
- **Expansion:** expand the patient experience data collection to larger numbers of patients and to specific communities of patients, with a view to understanding differences in patient experience amongst different patient cohorts and communities.
- **In-depth PPIE:** interviews with underserved communities to explore how health inequalities relating to treatment access are identified and acknowledged. Further work with patients who have declined an innovation or have not been offered an innovation (where clinically appropriate), to gain a better understanding of barriers in the system.
- **Deep dive:** explore the connectivity between innovation and health inequalities in patient access and experience.
- **Analysis:** granular analysis of experience and insights data for each product/innovation over time and across organisations will evidence impacts on experience of care across different patient groups and seek to mitigate any widening of health inequalities.
- **Promotion:** raising awareness of the framework at regional and national healthcare events.

Summary


1
Innovation project teams
2
Gather insight
3
What matters most to patients and carers?
4
Who can take action?
5
Commissioner
Supplier
HCP
Patient
1
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6
7
Care pathway
6
Action plan
7
Better Patient outcomes

Recommendations

We would like to express our appreciation for all those involved in developing the contents for the framework and report, with special thanks to all 29 patients who kindly offered their time to be interviewed and shared their valuable lived experiences throughout their patient journey and all members of our PPIE steering group.

We would also like to acknowledge the support provided by all the healthcare providers and charities: Ouch, Asthma + Lung UK and Action on Pre-eclampsia, who went above and beyond to help us reach out to patients.

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Appendix A

Additional information on the selected innovations

Spectra Optia: MTFM

Spectra Optia is an apheresis and cell collection device for the treatment of sickle cell disease, a group of inherited health conditions that affect the red blood cells. In a typical exchange procedure, Spectra Optia separates and removes sickle red blood cells from the patient's blood, which are then replaced with healthy red blood cells. See NICE Guidance.

Asthma Biologics: RUP

Asthma Biologics are an innovative group of medicines used by specialists to treat people with severe asthma. They provide a treatment option for people with severe asthma who continue to experience asthma attacks despite taking usual treatments (such inhaled steroids). Currently there are four NICE approved biologics for severe asthma (Omalizumab, Mepolizumab, Reslizumab and Benralizumab). See NICE Guidance.

Benign Prostate Hyperplasia (BPH) innovations: MTFM

Four innovations applicable to BPH were considered as part of the project:

- **UroLift** is an implant used to treat lower urinary tract symptoms caused by an enlarged prostate (a gland in the male reproductive system).
- **GreenLightXPS** is a device that uses a laser to reduce the size of an enlarged prostate.
- **Rezum** is a device that uses water vapour to remove excess prostate tissue.
- **PLASMA** (Bi-polar TURP) system uses electrodes to cut out prostate tissue, whilst stopping local bleeding.

As men age the prostate can enlarge and this is known as BPH. BPH can cause symptoms such as difficulty passing urine and not being able to empty the bladder completely. Because the prostate presses on the urethra, the bladder may have to use a lot of force to empty urine. Longer term, this can damage the bladder and kidneys. See NICE Guidance.

gammaCore: MTFM

gammaCore is a non-invasive vagus nerve stimulator and aims to modify pain signals by stimulating the vagus nerve through the skin of the neck. It is a non-medical treatment for adults who suffer from primary headache conditions such as cluster headaches. Cluster headaches are excruciating attacks of pain that can last between 15 minutes and 3 hours. Cluster headaches can be episodic, where patients have long pain-free intervals between attacks, or chronic. See NICE Guidance.

Placental Growth Factor-based Testing: MTFM

Placental Growth Factor-based (PLGF-based) testing is recommended by NICE to help rule out pre-eclampsia between 20 weeks and up to 34 weeks of pregnancy, in pregnant people who present with gestational hypertension but no other features. Pre-eclampsia is a multisystem hypertensive disorder of pregnancy that affects approximately 3% to 5% of all pregnancies and is associated with significant maternal and foetal morbidity and mortality. See NICE Guidance.

Appendix B

Getting it Right First Time's (GIRFTs) BPH Pathway with identified patient touchpoints for the four BPH innovations

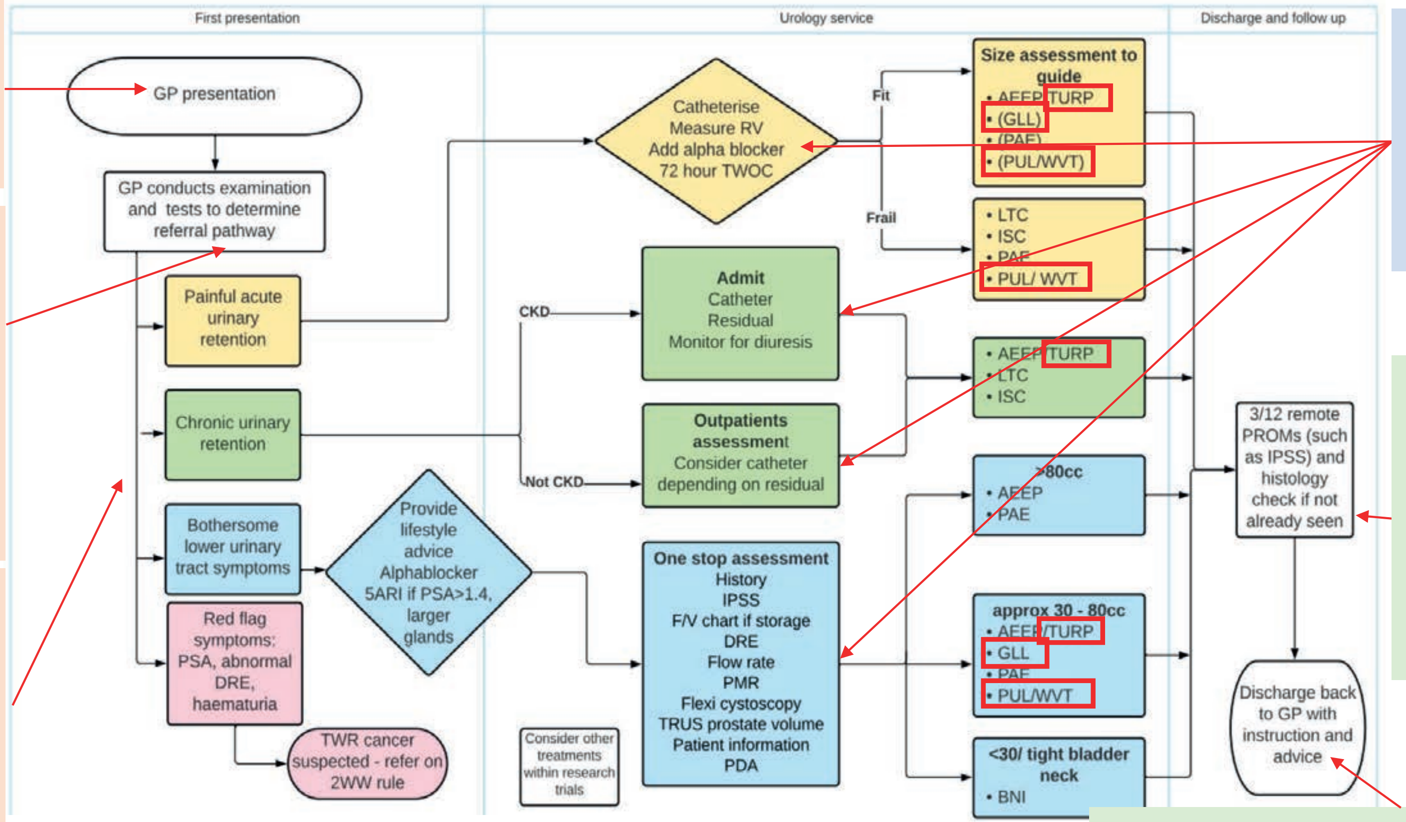
Patient Touch Point
Pre diagnosed

- May have researched symptoms
- Shared experiences from friends/family

Patient Touch Point
Initial or suspected diagnosis

- Patient presents to GP informs patient of possible treatments (may include surgery) however may need follow up assessment. To determine diagnosis, if cancer suspected.

Patient Touch Point
2ww referral patients into secondary care - no cancer concern. Patient given initial diagnosis, counselled on treatment option (lifestyle changes or medication).



Patient Touch Point – diagnosed/Pre Op

- Consultant to discuss treatment offer, provide patients with info (BAUS leaflets), discussing risk and benefits of treatments available?

Patient Touch Point
Post Op
PROMs - Patient-reported outcome measures - are increasingly used to measure patient's perspective of functional well-being, disease burden, treatment effectiveness, and clinical decision making

Patient Touch Point Post Op
What happens once patient is discharged, follow ups to determine treatment successful?

Glossary of pathway terms:

2WW	two-week wait urgent cancer referral	**PDA**	patient decision aid
5ARI	5-alpha-reductase inhibitors	**PMR**	post micturition residual
AEEP	anatomical endoscopic enucleation of the prostate	**PROMS**	patient reported outcome measures
BNI	bladder neck incision	**PSA**	prostate-specific antigen
DRE	digital rectal examination	**PUL**	prostate urethral lift
F/V	urinary frequency / volume chart	**RV**	residual volume
GLL	green light laser	**TRUS**	trans-rectal ultrasound
IPSS	patient satisfaction scores	**TURP**	transurethral resection of the prostate
ISC	intermittent self-catheterisation	**TWOC**	trial without catheter
LTC	long-term use of urinary catheter	**TWR**	two-week referral
PAE	prostate artery embolisation	**WVT**	water vapour therapy

Appendix C

Interview questions based on patient journey stages

To enable patient experience to inform the ongoing improvement of spread and adoption planning, the table below contains the questions that were used as part of patient experience data collection. These questions were also adapted for use with specific innovations, including amending or leaving out questions to align with the purpose of the innovation.

Patient Journey Stage	Patient question examples to support innovation need and use in patient journey stages
Stage 1: Open and honest conversations regarding concerns and worries	**Were symptoms/health issues understood? Can treatment or the innovation support?** • Were you able to share/explain your concerns? • Did you feel you were heard and listened to? • Were you provided with enough easy-to-understand information that you wanted? • What other support or information would have helped you understand your symptoms better or give you a better idea of how to get the most suitable help? • What would have made your experience of sharing details about your worries/symptoms better?
Stage 2: Initial diagnosis and options discussed and understood	**Is the innovation relevant? Can it be considered?** • What was your experience of getting told your initial diagnosis and the treatment options available? • Did you feel that you were provided with enough easy-to-understand information to make a good choice on what treatment is best for you? • Did the member of staff you spoke to seem well informed? • What other information/support would you like to be provided with to help understand what treatment options are most suited to you? • Did you feel involved in the decision making?
Stage 3: Expectations and potential issues clearly discussed, and treatment started	**Is innovation to be used at this point?** • What was your experience of understanding and discussing expectation and potential issues with treatment? • Are there any challenges you faced which prevented you from using your treatment properly? • Do you think there are any barriers to being able to use this treatment properly? • Did you feel involved in the decision making when starting the treatment?

Patient Journey Stage	Patient question examples to support innovation need and use in patient journey stages
Stage 4: Patient experience on initial treatment shared and listened to	**Was treatment successful?** • What opportunities did you have to tell a healthcare professional about how you got on with your treatment? • Did you feel like there were enough resources available to you to help you understand what options were available? • Did you feel listened to? • What was your experience of having dedicated time to discuss the different options for next steps? • What would have improved your experience?
Stage 5: Alternative 'innovation' introduced based on shared decision - access and barriers resolved	**Is the innovation used, now required?** • Did you feel well informed in understanding your new treatment? • How long did it take to access your treatment and did this cause any problems? • Did you need support to understand and access your treatment/appointment? E.g., travel, translator • What would make starting your new treatment trouble-free?
Stage 6: New treatment reviewed to assess degree of patient satisfaction	**Initial impact of innovation** • Were you given the opportunity to share your thoughts about your new treatment? • How long did it take to get your treatment reviewed? • Would you recommend this treatment to others and why? • What would have made your treatment experience better?
Stage 7: Agreed decision on long term care plan	**Long term impacts of innovation** • Were you provided with enough information to understand your care plan and/or future steps? • In what ways has your day-to-day life improved? • On reflection, were there any barriers/ delays in accessing this treatment? • Do you think you have enough easy to understand information or resources to enable you to continue to live your life after/whilst using the treatment?

Appendix D

Related reading

NHS England

National statutory guidance[6] published by NHS England in July 2022 requires Integrated Care Boards, NHS trusts, foundation trusts and NHS England to meet their public involvement legal duties and the new 'triple aim' of better health and wellbeing, improved quality of services and the sustainable use of resources.

The NHS Outcomes Framework (2022)[7] sets national outcome goals enabling the Secretary of State for Health to monitor the progress of NHS England.

The National Institute for Health Research

The National Institute for Health and Care Research (NIHR) provides patient and public involvement guidance and resources[8] for applicants to NIHR research programmes. These include UK Standards for Public Involvement in Research, guidance for researchers on PPIE, co-production and resources for evaluating the impact and reporting of patient engagement.

Health Innovation Network, University of Plymouth and Boehringer Ingelheim

In May 2022, the Health Innovation Network in collaboration with the University of Plymouth and Boehringer Ingelheim conducted a review of best practice in patient and public involvement and engagement to provide advice and guidance to digital innovators. The aim of the review was to provide a practical guide[9] to bring forward innovations with the patient, not for the patient. Developed using rigorous academic Delphi methodology with a diverse range of stakeholders, the evidence-based principles seek to support innovators to use co-production approaches in digital health innovation from start to finish.

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[6] Working in partnership with people and communities: statutory guidance, NHS England » Working in partnership with people and communities: statutory guidance

[7] The NHS Outcomes Framework, https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/march-2022

[8] National Institute for Health and Care Research PPIE resources, PPI (Patient and Public Involvement) resources for applicants to NIHR research programmes | NIHR

[9] How to involve and engage patients to NHS buyers for free in digital health tech innovation, Principles of Patient and Public Involvement and Engagement (PPIE) | boehringer-ingelheim.co.uk

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