

Making Innovation Work for People

Surfacing Unmet Need

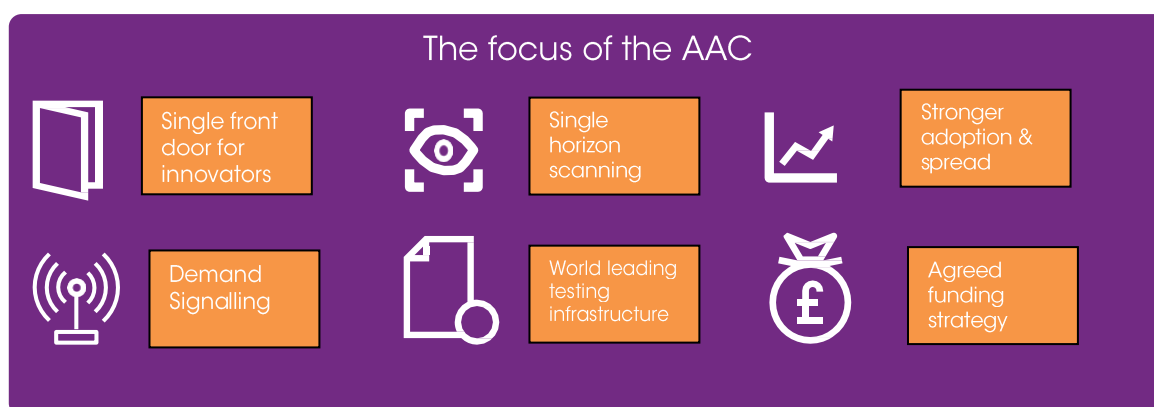
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Introduction

In August 2019 National Voices was asked by NHS England and NHS Improvement to undertake research and engagement to uncover the unmet needs of patients, service users, carers and their families managing long term conditions. The aim being to help inform the work of the **Accelerated Access Collaborative**¹ (“AAC”) in supporting the spread of innovation across the NHS and identify areas where more research is needed.

The AAC brings industry, government and the NHS together to remove barriers to the uptake of innovations across the NHS. National Voices has been a lead partner in the AAC since its inception. Our Chair, Hilary Newiss, co-chaired the collaborative in its early stages and still represents National Voices and the wider patient voice sector on the board of the expanded AAC.



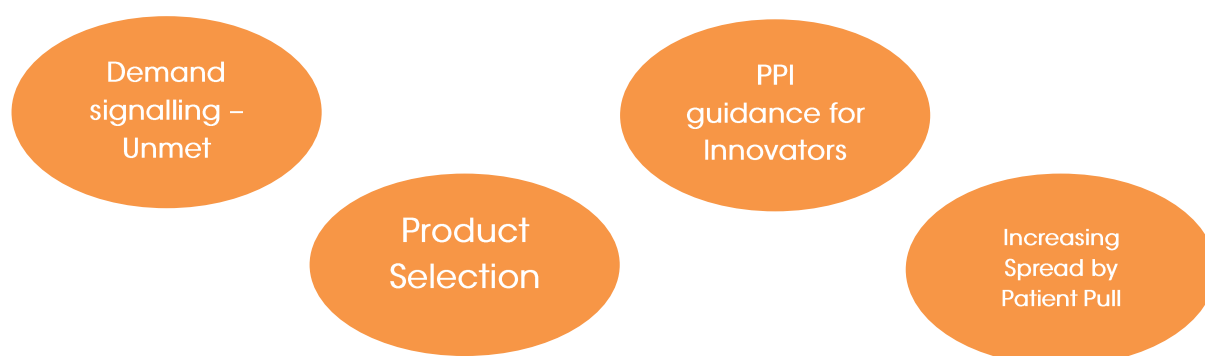
Along with colleagues at the Association of Medical Research Charities (“AMRC”) we have helped develop patient engagement content for the AAC, contributing our “[I statements](#)” outlining the values people who need services need to see represented in research and innovation.

We have long believed that it is crucially important the priorities and unmet needs of people who actually use or depend on services shape all decisions about how care is designed and delivered, and this includes the decision-making process around which innovation is prioritised and rolled out across the NHS and what research priorities should be. We are therefore excited that NHS England and NHS Improvement have also recognised the

¹ [The Accelerated Access Collaborative](#) brings industry, government and the NHS together to remove barriers to uptake of innovations. Its aims include driving the uptake and adoption of innovation in the NHS and identifying and supporting innovations that will deliver the most benefits for patients.

importance of these issues and asked for National Voices involvement in this latest work.

Both National Voices and AMRC have worked closely with the AAC team at NHS England and NHS Improvement over recent months to shape how our member organisations input into the following AAC programmes of work:



Our main focus during this time has been to identify the unmet health and care needs of people across the county who live with long term health conditions and to highlight areas in which research or innovation may help to provide solutions.

Much technological innovation seems to be driven by those **developing** the technology and those people don't always start by looking at the **unmet needs of the people they are trying to help**. Evidence of these unmet needs surface at different points across the health and care system and rarely in settings where it will be easily picked up by innovators looking for opportunities to help. Identifying unmet needs require us to ask questions, to listen and to understand what it is that people value when they live with ongoing health problems.

This is where patient organisations can play such an important role. They maintain close relationships with the people they support and engage with them outside clinical settings, often over long periods of time. It therefore makes sense to work with patient organisations in order to surface and collate their insight about the unmet needs and priorities of people who need health and care to work better.

Ultimately understanding unmet need better will help us to design health and care that creates true value – and given healthcare resources are always limited, this focus on where innovation will make the most difference is crucially important.

Our Research

During September 2019 we engaged with our members and the wider health and care charity sector on the subject of people's unmet needs and priorities. We issued a request for the following information:

- a. Details of current and potential future unmet needs identified by your own beneficiaries, plus details of successful methods you have used to uncover unmet needs; and*
- b. Any priorities identified by your beneficiaries in addressing those unmet needs.*

We received a total of 22 responses to our request. Most of the responses were detailed reports recently completed by members uncovering unmet needs and identifying priorities. We also conducted a number of telephone interviews with organisations to better understand the focus of their work and their findings.

Qualitative analysis of all the evidence received revealed that despite the number of different health conditions managed by people across the country there are **clear cross cutting themes** when it comes to their unmet needs. These themes echo those highlighted in a number of recent reports on management of multiple and/or long-term conditions². Our hope is that by capturing them in this report we can begin a conversation between patient organisations within the voluntary sector and innovators in order to focus innovation on where it matters most and will therefore create the most value.

²["Multimorbidity: Understanding the Challenge"](#) The Richmond Group of Charities Jan. 2018.

["Just one thing after another: Living with Multiple Conditions"](#) The Taskforce on Multiple Conditions Oct. 2018

["Understanding the healthcare needs of people with multiple conditions"](#) Health Foundation Nov. 2018

["The Multiple Conditions Guidebook"](#) The Taskforce on Multiple Conditions Nov. 2019

Summary of Findings

At the most generic level, what people talk about when they describe what they need help with when living with ongoing health problems is “**cop**ing”. People from many different backgrounds, at many different times of life find themselves having to cope with the impact of a particular condition on their lives. Clearly people’s ability to cope depends on many other factors: whether they have the material resources to live well, whether they have people who look after them and care for them, whether they are experiencing other pressures (violence, worklessness, poverty etc).

Much of this is outside the control of health and care, and not accessible to innovators in health either. But there are also things that can happen inside the health and care system that enable or undermine people’s ability to cope. Our research has shown that the health and care related needs of patients, carers and families seeking to cope with the impact of ill health can be broken down into the following main categories:

- a. Information Needs*
- b. Holistic Care*
- c. Coping Long Term*
- d. Family Needs*

a. Information Needs

Problems with communication and provision of information feature heavily in all the research carried out by patient organisations. Broadly speaking **a significant number of patients, service users, carers and families are not getting the information they need, at the right time, in the right format.**

As discussed in more detail later, the evidence provided to us in our research is the result of numerous national surveys and consultations across groups of people with a variety of different conditions. Problems cannot simply be blamed on regional disparities in the quality or configuration of services. Information that will help patients, carers and families is not finding its way to them in an accessible form at the right time for them. By way of illustration:

- Patients still struggle to get access to information about their condition when they need it. More than 10,000 people responded to the Neurological Alliance's 2018/19 [National Patient Experience Survey](#). 43% reported that at the point of diagnosis they **did not receive the information they needed** about their condition. [Reduce, Improve, Empower](#) published in 2018 gathered the experience of over 2,000 people living with rare autoimmune rheumatic diseases. 40% felt they didn't get enough information to help them live their lives and relied instead on the internet.
- Patients felt they needed **increased access to information at initial diagnosis** and throughout the early months of coming to terms with their condition. Instead people report being handed a leaflet at their first appointment and being told to "live their life". The current Bloodwise campaign [Hear Our Voice](#) captures stories from people with chronic blood cancers, many of whom feel anxious about their initial cancer diagnosis but then are then left confused by the fact that, notwithstanding their diagnosis, they may not need treatment for years.
- Information provided by health professionals about procedures and treatments is often lacking the benefit of **feedback and input from those who have already experienced** them due to the fact that there is no effective means of feeding back patient experiences. For example, Jo's Cervical Cancer Trust's report [Not So Simple](#) compares advice given to women before they undergo a colposcopy with the real life experiences of those women undertaking that procedure.
- In some cases, **GPs and other health professionals themselves need more information and training** in order to provide the support that patients need. Compassion in Dying found that people contacting their GPs to make [advance plans](#) for their end-of-life care and support in order to relieve their families from unnecessary stress later on, often received conflicting advice about the options available to them, or no advice at all.

43% did not receive the information they needed

b. Holistic Care

The desire to be **treated as a person, not a condition** is felt strongly by those managing long term conditions. Being treated as a whole person, means receiving emotional and psychological support as well as clinical treatment. The importance of emotional and psychological support has been highlighted in different reports over a number of years. An example of one of those earlier reports is the 2012 joint report by The British Heart Foundation, Diabetes UK, Macmillan Cancer Support and others ["Twice as](#)

Likely – putting long term conditions and depression on the agenda”

highlighting a **strong link between depression and long-term conditions**. Our member organisations have produced many more recent reports confirming that, unsurprisingly, people’s needs haven’t changed. An example of one of those more recent reports is the Diabetes UK 2019 report [Too Often Missing](#). This latest report gathered evidence from 2,000 people with Type 1 and Type 2 diabetes and over 1,000 GPs and other health professionals on the importance of emotional support to diabetes patients.

A common finding in these reports is that when people struggle emotionally and psychologically it can have a **negative impact on their behaviours** which, in turn, can have a direct impact on their health. This impact is felt across many different conditions. By way of illustration, the Diabetes UK report highlights that a person with diabetes may fail to take insulin, or to follow the right diet which can result in rise in blood sugar levels. Equally, a person with osteoarthritis, also needs to maintain a good diet and stay active to manage their condition well, as illustrated in studies by [Versus Arthritis](#).

Even with evidence such as this, our research has shown that there is still a way to go before the right package of emotional psychological and physical treatment and support is provided to everyone. Key issues identified in our research include:

- Support provided at first diagnosis tends to be focussed on clinical information about a condition. The **emotional impact of receiving a diagnosis** is often devastating and left to patients and family members to manage on their own. The need for emotional support also rises around **significant life events** which rarely coincide with scheduled appointments.
- Long term conditions can have a profound impact on a person’s life and yet **practical advice** on this impact and how to manage it is often not provided, leaving patients, carers and families researching local support groups to gain answers to many of their questions. A 2019 survey by the [MS Society](#) revealed that 1 in 3 people with MS do not get the help they need with **everyday living**. [Asthma UK](#) set up a Whatsapp helpline service to connect people to asthma nurses and found a surprising number of people were requesting authoritative consumer **product recommendations**. Support required is often not clinical or therapeutic at all, but **assistance with life admin or practical challenges**.
- At present, emotional support (such as there is) and clinical support are often linked meaning that emotional support falls away in between scheduled clinical appointments. Current research by [Macmillan Cancer Support](#) has shown that those managing long term conditions need **continual personalised access to emotional**

support between appointments. People living with cancer express a need for support months and even **years after treatment finishes**, but the support drops away at the end of the treatment. [Bloodwise](#) report **increased anxiety** amongst the people the support in periods between clinical appointments when **support is not available** to them.

- Those people placed on “**watch and wait**” to see if they develop a particular condition are treated clinically as not having a condition until it materialises. Whereas [Prostate Cancer UK](#), Macmillan Cancer Support and other cancer support charities report that the **emotional and psychological needs** of people on “watch and wait” pathways are often no different to a patient with the condition when it comes to information and support needed.
- The offer of **emotional support is not consistent across conditions**. [Changing Faces](#) found that those patients with facial disfigurements caused by skin conditions are **not routinely offered emotional support**, while those whose disfigurement is caused by burns, for example, are offered support. Their [Look At Me](#) campaign launched in 2012 highlights the similarities in the emotional and psychological impact of both types of condition and lobbies for **consistent emotional and psychological support** for all.
- Patients need the **ability to speak freely** in professional and peer groups settings **without fear of upsetting their families/carers**. Many seek peer support because they need to **feel understood, accepted** and be surrounded by those who know exactly what they are going through. Peer support is highlighted in [Too Often Missing](#) as something that would help those living with diabetes who often feel stigmatised by others who do not have their condition. Many of our member organisations host online community forums where people can support each other on a wide range of issues from understanding initial diagnoses to support with everyday living. New visitors to these communities can also be monitored by patient organisations to identify newly diagnosed people or others who are **struggling with their condition** and may need additional support.

“The offer of emotional support is not consistent across conditions”

c. Coping Long Term

Access to the right information, in the right format, at the right time can dramatically improve the ability of patients to manage their long-term conditions. What if access to information reflected **how people actually live** their lives, so that wherever they were, at whatever time, they could access

what they needed? What if the creation of medical records focussed more on the **needs of the patient** instead of the system? What if medical records were patient facing to allow **input and self-referral** by patients?

Such improvements could dramatically improve the ability of patients with long-term support needs to manage their needs outside of a clinical setting:

- [The Palliative and end of life care Priority Setting Partnership](#) was set up in 2015 by a number of palliative care patient organisations including members [Marie Curie](#) and Macmillan Cancer Support. Its aim was to identify and prioritise a series of **unanswered questions** in palliative and end of life care. A key priority identified was to make symptom management, counselling and advice, GP visits and 24-hour support available beyond traditional hospice settings, **allowing people to choose where they receive support**.
- Patients with long-term conditions often have more than one. There is still a tendency for the NHS to manage each condition, with separate records. As result, patients are left **managing multiple records** wherever they go. Alternatively, people may need to access **multiple health professionals** for their one condition. Once again, each health professional creates a separate record, leaving patients to manage multiple records wherever they go. The **burden on people managing multiple conditions** is well documented in the reports referenced in the Our Research section at the beginning of this report but can be felt most acutely by those with **musculoskeletal conditions** where movement can be restricted and where a **large number of older people** are affected. This Versus Arthritis [report](#) discusses the problems in more detail.
- Many patients with long-term conditions **quickly become experts** in **understanding the impact** of that condition and associated treatments on them. However, significant numbers of them still do not feel that they are adequately involved in decisions about their care. The Neurological Alliance's 2018/19 patient experience survey report [Neuro Patience](#) confirms that 30% of respondents **didn't feel they were involved enough** in decision about their care. [Versus Arthritis](#) report that only 12% of people with musculoskeletal conditions have a care plan. The [British Heart Foundation](#) reports that the people they support want patient facing records to help **improve self-management** and alignment of the care team.

30% did not feel they were involved enough in decisions about their care

d. Family Needs

The concept of holistic care recognises that **patients do not exist in isolation** and the impact of any medical condition can be felt by more than the patient themselves. Carers and patient needs are related but can also be different. Both lose out if they cannot download their concerns without fear of burdening the other.

**“Patients
do not exist
in isolation”**

Many of our members realise this and offer **separate and bespoke support offers to carers and patients**. Many offer peer support forums where parents and carers are free to speak and ask questions without worrying about upsetting the patient. They also campaign for **better understanding by health professionals** and other support services of the support needs of families and carers as distinct from the needs of the patient for whom they care.

Meeting Needs

In addition to uncovering evidence of these cross-cutting themes, our research has also highlighted the vast amount of work patient organisations do developing solutions to the specific needs of the people they support. In addition to finding solutions to some cross-cutting needs, our member organisations spend time researching earlier or faster diagnoses and improvements to treatments. We believe this report is an opportunity to highlight some of this work to innovators and we know that patient organisations are keen to see that happen.

Our wish and theirs is to start a long-term conversation between the voluntary sector and innovators focussed on how each can help the other to address significant unmet needs.

Our research uncovered a range of different examples covering a wide range of needs. Examples include:

- Patient organisations including [Marie Curie](#), [Parkinson's UK](#), [British Society of Gastroenterology](#), [The Urology Foundation](#), [Alzheimer's Society](#) and [Guts UK](#) that had been involved in different priority setting partnerships ("PSPs") on single health issues came together to identify unmet needs arising across different PSPs and established that continence issues were relevant for people with many different health conditions. Their work culminated in a joint workshop report "[My Bladder and Bowel Own My Life](#)" which identifies a number of technological solutions that could help meet the needs of those with continence issues.
- [Compassion in Dying](#) is running a peer-led project in Lambeth, south London to raise awareness and take up of advanced care planning across the borough. The ambitious project seeks to improve relationships and communications between families and healthcare professionals, reduce barriers to accessing healthcare and ultimately allow people more control over planning end of life care. Reports on the early work can be found [here](#).
- Diabetes UK has identified a number of [priorities](#) for patients with Type 1 diabetes including reducing hypos, exploring the effectiveness of different insulins and technologies, and further research into the artificial pancreas that monitors blood sugar levels and then automatically injects the right amount of insulin.

- The MS Society is looking to expand a number of existing [digital tools](#) that manage particular MS symptoms or sets of symptoms into a more comprehensive solution that will allow MS patients to manage their own lives more easily. Through an MS Technology Forum it is hoping to co-design new digital self-management tools with MS patients
- Raynaud's Disease and Scleroderma are currently difficult to diagnose in many scenarios due to the lack of common knowledge of the conditions. [Scleroderma & Raynaud's UK](#) have included within their most recent [research priorities](#) the standardisation of tests to improve early detection of both conditions and to increase access to those tests outside specialist settings.

There are many more examples, and a much wider need for innovators to be more curious about the work that goes on in patient organisations. We would be keen to play our part in making such innovations more effective and strategic.

Conclusions

It is clear from the responses received that there is rich data held by patient organisations about current unmet needs of patients, carers and families living with long-term conditions. We believe this report represents an opportunity for patient organisations to work with innovators across the NHS to seek to address these needs in urgent and strategic ways.

We see many opportunities for patients with long term conditions to play a bigger role in the management of their condition for better outcomes and better quality of life. This does not mean people can be left to their own devices. It means that statutory health services need to think harder about what will help a person and their family **COPE**. The answer for many will include support from patient charities, peers, and the wider community. We feel this is a rich seam of thoughts innovators and researchers could explore much more urgently:

- What would it look like to enable healthcare professionals to provide better, relevant and real-life information to patient and carers at the point of diagnosis?
- What would need to happen for patients and carers to be supported with good information and advice throughout?
- What solutions could be developed that link people into peer support from the point of diagnosis or at other significant points during their health journeys?
- How can we accelerate solutions that help bring all the various bits of information about a person's clinical and non-clinical needs together and enable this information to travel with the patient to where their life and illness takes them?

We feel a better shared care record will go a long way to meeting those needs, but we need to be careful that this record enables people to shape the care they need and want, based on what needs they have and priorities they want addressed. This needs to allow patients to input their own experiences of managing their condition, building a truly personalised care plan with health professionals.

It might seem that we have heard much of this before. Indeed, we have highlighted above a number of major reports dating back a number of

years that raise many of the issues. However, with the advent of Universal Personalised Care, Primary Care Networks and, of course, the AAC the environment may now be right for strategic and impactful innovation in these areas.

It might also seem that these needs are hard to meet through the kind of innovations we have seen in recent years: discrete interventions at a single point of a complicated pathway – ignoring that people often don't neatly travel down these clinical guidelines in real life. But we feel this is the actual challenge: The needs people have and which we have surfaced here will not be met by small clinical improvements. They require a focus on the conversations that happen,

the handovers, the interface between health and life, and services and families. This does not mean that there isn't much potential for thoughtful innovation: We need to focus innovators' minds on these connections, on the spaces between clinical appointments, teams, and tests, - it is those spaces where people's lives take place, and where good or bad health outcomes and good or bad quality of life is taking shape.

“The needs people have and which we have surfaced here will not be met by small clinical improvements. They require a focus on the conversations that happen, the handovers, the interface between health and life, and services and families.”

Methodology

Our own methodology has already been highlighted at the beginning of this report. Of greater interest is the range of methods used by the patient organisations responding to our request in uncovering the unmet needs of their beneficiaries:

- Regular annual/bi-annual/tri-annual surveys issued across their entire recorded membership creates a continual dialogue between the organisations and their beneficiaries on major issues.
- Online questionnaires tend to be used either for annual surveys or targeted research.
- These results are then followed up with phone interviews with a number of respondents to understand underlying reasoning in more detail.
- Online forums created for networking between beneficiaries and/or families also provide opportunities to gather views on current issues.
- Technology and research groups created to test new technical and research initiatives can also be used to consult with specific groups of beneficiaries.
- Regular networking and training sessions for health professionals create additional consultation opportunities with them (as well as education) to provide a more detailed understanding of issues affecting patients.

Acknowledgements



We are grateful to all who responded to our request for information, both members and non-members:

- Action Against Allergies
- Asthma UK
- British Heart Foundation
- Bloodwise
- BME Cancer Communities
- Changing Faces
- The Cystic Fibrosis Trust
- Compassion in Dying
- Diabetes UK
- Jo's Cervical Cancer Trust
- Living Better
- Macmillan Cancer Support
- Marie Curie
- MS Society
- National Aids Trust
- Neurological Alliance
- Pancreatic Cancer UK
- Prostate Cancer UK
- Shine Cancer Support
- SR UK
- Versus Arthritis
- We Hear You

National Voices

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 160 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

020 3176 0738

info@nationalvoices.org.uk

www.nationalvoices.org.uk

18-20 Bride Lane,
London,
EC4Y 8EE

