Patient Advisory Group Summary Report

15th August 2024

Executive Summary

7 patients[1] from US, Europe & UK with a variety of conditions, & experiences

Patient Advisory Group: improving understanding of the needs & wants of patients experiencing sampling

Common Themes

Patient-centred care is important: Solution development doesn't value patient experience

Linkage: Patients currently have the burden of linking healthcare and self advocating, without shared control over their health. E.g. have the data go to all members of multidisciplinary team needed without patient having to be the constant advocate – time spent on shared decisions based on data, not sharing data

Psychological & emotional impact: The sampling process and environment can be traumatising

Autonomy & empowerment: need results in time so that they can react to symptoms & coordinate management of condition

Logistics: need enough supplies (equipment) in case something goes wrong, pre-addressed & affixed postage, smooth & connected process

Solutions

Guidance: Clear and updated instructions demonstrated by a patient, with pictures and videos support

Provision of supplies: timeliness, the right materials, enough equipment

Solution & process design: Use an approach that enables patients to have more control over daily health and interact better with physicians

Automation in a process or solution is preferable

Meet needs: Different situations and people may need different solutions – listen to the needs when designing

Recommendations for PCSIG

Work with patient groups to support, provide insight and spread the work of the work of the PCSIG

Involve patients in continuous development and design of processes and solutions

Direct engagement & specialist patient groups – elderly, neurodiverse, disability groups, children and parents etc.

PCSIG Patient Advisory Group: Insights summary

August 2024

1 Experience of providing samples

Logistics

Time, uncertainty, burden of arranging/chasing

Patient centred care

Solution development doesn't value patient experience

Quality of care

Frequent problems & patients left to resolve

Psychological & emotional impact

Sampling process, as well as physical and social environment can be traumatising

Shared decisions & being heard

Need to be respected and know how to advocate

2 Involving patients in solution development

Why?

Patients feel the consequences of healthcare decisions and processes in a way that is normally unseen. Different perspective on what 'good' looks like. Greater insight into what influences patient choice and experience

What?

Empower patients to have more control over daily health and interact better with physicians

Impact

Improved healthcare management and financial savings for healthcare systems

3 What patients want from PCmS

Logistics & supplies

Having enough & right supplies, ensuring transported okay, simple approach, address labels clear & attached

Test administration & results

Safety, timely results, clear monitoring, preference for automatic solutions. Good instructions are critical

Social & personal attributes

Travel, stigma, & accessibility

Improved interaction with healthcare systems

Help with linking up sampling & the different healthcare systems

4 Interacting with PCSIG in the future

Patient power & influence

Patient voice can help communicate and amplify aims of PCSIG

Promotion & collaboration

Patient involvement encourages other patients to advocate for improved sampling

Cost savings & patient adherence

Clarify and promote the difference good sampling/ monitoring can make for patients – reducing likelihood of more intrusive healthcare, and being able to take better care of own health

Report contents

Introduction

Background, people and process

Background

The Meeting

7 patients[1] representing a variety of conditions, countries, and experiences met for a Patient Advisory Group. The meeting was attended by the chair of PCSIG, Neil Spooner, and run by MediPaCe.

TIMELINE

About the PCSIG

The Patient Centric Sampling Interest Group (PCSIG) is a not-for-profit organisation that brings together interested parties who wish to develop and promote the use of patient centric sampling technologies for blood, plasma, urine and other human matrices to better facilitate the advancement of human healthcare and well-being.

Meeting Purpose

To gain a deeper understanding of the needs and wants of patients experiencing sampling, what impact it has on their lives, and the type of relationship and role patients want in sampling and within future PCSIG work.

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[1] The word ‘patients’ is used throughout this report to represent patients and their supportive network of family and friends that are also affected.

People and Process

PEOPLE

- 7 patients and carers[1]
- Range of experience in trials, healthcare systems, health monitoring needs, patient organisations
- Diverse range of conditions included rare, genetic, neurodegenerative, hormonal & inflammatory diseases.
- From the UK, Europe & US.

PROCESS

- 2 ½ hour facilitated online meeting
- Perspectives and insights were gathered on:
  - Experiences of providing samples.
  - Impact of sampling on patients
  - Ideas of what's needed to make sampling easier
  - How patients would like to interact with PCSIG in the future

Discussion 1

Experience of providing samples

Participants were asked to share their experiences of providing samples, such as urine, blood, salvia and other bodily fluids. They were prompted to think about anything related to managing their own condition or chronic symptoms such as challenges and frustrations encountered during the process, anxieties or concerns associated with the procedure and any reflections of taking part in clinical trials. As well as any relevant feelings of being a parent, carer or family member.

Key themes: Experience of providing samples:

LOGISTICS

PATIENT-CENTRED CARE

QUALITY OF CARE

PSYCHOLOGICAL & EMOTIONAL IMPACT

SHARED DECISIONS & BEING HEARD

Experience of providing samples

Logistics

“I could be lucky, and it would take half an hour, or I was unlucky, and I would sit there for two and half an hour”

Key Advice

Awareness and planning of sampling needs carried in people’s heads all the time. These include:

- Time and arrangements for travel to clinics
- Unpredictability and uncertainty about duration of appointment impacting on rest of day planning
- If choice given, would prefer an appointment at a closer clinic but this usually means a longer wait for results
- Difficulty booking appointments– especially if symptom based monitoring and quick turn around needed
- Burden usually falls on the patient for: arranging, chasing for results (and sometimes correct tests), sometimes transfer of health information to new clinic

“The hospital that I'm treated at is like an hour from my house. And it takes both ways, of course. So, we take like half a day for me to actually just like go and get a blood sample”

Experience of providing samples

Patient centred care

"I think as patients we're already sort of starting our day at a deficit….. Just there's a lot of thought process, energy, time, so many different factors that play a role into this for us"

Key Advice

The patient needs to be at the heart of healthcare delivery but current processes do not seem to account for patient preferences and needs. Highlights include:

- Patients are affected by physical and mental pressures which cause additional hardships and stress.
- Consideration needs to be taken around a person's personal circumstances and intersectional factors, such as disability, socioeconomic status, ethnicity, age, gender etc.
- Patients are experts in their own health condition and what works best for them. The patient-professional relationship should be collaborative to ensure patient needs and medical expertise align for a positive outcome.

"And I don't actually know what to ask for….I know that he [my son] needs tests but trying to convince the GP what we may or may not need, because I think at this stage she's getting a bit fed up with me asking"

Experiences of providing samples

Quality of care

“When I was in the hospital, we did a 24-hour urine [sample]. They actually spilt it… and I had to redo it. And I was like, my God! we've been doing this for so long and now we have to do it again!”

Key Advice

Good quality of care is important to ensure patients get what they need, engage in their own health management and get health outcomes are met. Reports were made about the following:

Samples can be contaminated or lost. The process of providing another is stressful, painful and burdensome.

Miscommunication/errors can occur, for example, the wrong equipment is provided, or samples haven’t reached the doctor. This often impacts directly on the patient who have to liaise between staff and departments and/or obtain new sample kits or make a new appointment.

Patients also have to navigate inconsistencies with results depending on the type of sample. This causes them to be nervous about certain types and providers of sampling kits.

“I would say at least half the time, I would have to go back up to my doctor's and be like “there's no testing” and then I have to wait to actually just talk to my doctor, which usually also takes half an hour and so yeah, that's a massive issue”.

Experience of providing samples

Emotional and psychological impact

> “Just something simple like having a blood test can be impossible, actually, because [children] they’re so traumatised by all the interventions that they've had, that even just getting the blood sample from them is impossible”

Key Advice

Sample collection can be traumatic for some patients, especially in clinical settings with bright lights and noisy waiting rooms, which can heighten anxieties. This can be particularly challenging for those with neurodivergence, young people and/or those with disabilities. Additionally, medical staff dressed in “white coats” cause distrust and fear.

Patients report suffering with PTSD from simply being from being in a clinical environment, or from providing regular or especially lifelong samples.

Stigma was reported by attendees at some clinics, especially when needles are involved. Social norms and stereotypes can cause embarrassment and shame, but the option to sample privately at home can alleviate these factors.

> “Things like bright lights. Certain sounds, especially for people who are triggered, triggered by misophonia, which is sound sensitivity. Just being in that kind of clinical atmosphere is incredibly, incredibly traumatising for some of these people”

Experience of providing samples

Shared decisions and being heard

Key Advice

This theme covers a few different elements. It was felt that medical staff do not appreciate that the patient knows their body the best and have been providing these samples and tests for years. Patients feel that they struggle to be heard and find it difficult to get the tests they need.

Patients also report that it is beneficial to have some medical knowledge as this helps to advocate for yourself. However, not many patients have this background and so many rely on the expertise and recommendations of their doctor.

"The nurses in my infusion centre, they'll add it for me [a test] and they're not really supposed to!"

"Looking at the perspective of somebody that maybe doesn't have any medical background. I would imagine that they're completely lost, 'cause how do you know what to ask for?

Discussion 2

Exploring the impact of involving patients in solution development

Why is it important to improve how samples are taken? How by involving patients can healthcare professionals optimize a new approach. With all perspectives integrated into the solutions, healthcare and patients can partner together better in real life to enhance patients’ experiences, care and quality of life.

Key themes: Involving patients in solution development

WHY?

Patients experience the consequences of healthcare decisions, processes and delivery in a way that is unseen by healthcare professionals, and it brings a completely different perspective on what ‘good’ looks like.

WHAT?

If solutions also address patient needs then they have more awareness and control over their own condition. They can work better with their care team and actively partner with them on achieving the best outcome.

IMPACT

Solutions that work for patients, as well as greater patient autonomy and ability to partner well with their healthcare providers, results in improved healthcare management and financial savings for healthcare systems.

PCSIG

WHY?

Involving patients in solution development

"And I think if you ask anyone, truly, if about the hassles and the difficulties of going for blood tests all of the time, I don't believe that anyone would tell you it's a great experience."

"I think it's even more important that you hear from patients who are willing to give their real thoughts because, there is still that divide in society, a lot of the time……people will still just say yes, yes, yes. "

Key Advice

Patients, because they are directly impacted, often experience the barriers and challenges in healthcare that might not be obvious to medical teams. It is this viewpoint that can help to develop practical solutions. Participants highlighted the enthusiasm and willingness of being newly diagnosed, where you often accept more than you would compared to your feelings and experiences of being a long-term patient. This insight can not only help identify issues others may not see, but it can also help ensure chronic patients stay engaged in their care.

Patients emphasized the importance of 'real' truthful feedback. Medical staff can be seen as authoritative experts and systems can be seen to be complex and unchangeable. This can hinder patients from being honest, trusting their own judgements and feeling that their experiences are not valuable.

WHAT?

Involving patients in solution development

Key Advice

Participants highlight how important it is for patients to feel in control and empowered. The powerful effect this can have on their mental health, anxieties and stress is clear Participants also shared that being able to regularly monitor their own health quickly and easily, and in a way that suits the patient, again, reinforces this sense of control and empowerment. Not only tha,t but in a lot of circumstances it can help with health management. For example, glucose monitoring for patients with diabetes or rare diseases where day-to-day monitoring is vital for symptom management.

Easy monitoring, quick and easy booking-in systems (for tests), efficient communication with experts with a sense of autonomy over their own health helps patients better engage in their own care.

“If you're not able to get the samples you don't have control, you know, so that's when it gets scary, it gets frustrating…I think it's extremely important to feel empowered.”

“Just having something where you could just test it right away and then just like push it out of your head and not have to worry about it for 24 hours.”

IMPACT

Involving patients in solution development

"Just being able to take the test and just be sure, like, "there's nothing wrong, it's just the withdrawal symptoms, it's not a sign that I'm going into [hypo], would just be like so much easier and not having to go to the hospital all the time."

Key Advice

Patients provide a different perspective and unique insights which can help with the adherence and adoption of treatment and care. This alongside ensuring patients feel empowered, in control and treated with a sense of dignity will not only improve health outcomes but will also make cost savings for healthcare providers by reducing complications and re-admissions.

With conditions that require consistent monitoring, putting the control in the patient hands can lead to improved health. Not only does it alleviate worries and anxieties about what is happening to their bodies, but it allows them to take action, reducing the need for more time-consuming, potentially distressing and invasive or expensive treatments.

Staff do not appreciate that the patient knows their body the best and have been providing these samples and tests for years. Patients feel that they struggle to be heard and find it difficult to get the tests they need.

Patients also report that it is beneficial to have some medical knowledge as this helps to advocate for yourself. However, not many patients have this background and so many rely on the expertise and recommendations of their doctor.

Discussion 3

What do patients want from patient centric microsampling (PCmS)?

Patients were asked to share their ideal solutions, what they will need help with, and about practical or social implications that might be of concern.

Key themes: What patients want from PCmS

LOGISTICS & SUPPLIES

TEST ADMINISTRATION & RESULTS

IMPROVED INTERACTION WITH HEALTHCARE SYSTEMS

SOCIAL & PERSONAL ATTRIBUTES

What patients want from PCmS

Logistics and supplies

Key Advice

Participants highlighted the issues they have experienced with ensuring that they have the correct, and enough, supplies to administer home sampling.

Participants also talked of worries with packaging and posting samples, ensuring they were protected and arrived safely so that results could be obtained quickly and accurately. They also highlighted that this process needs to be simple, with the correct protective equipment provided and clearly addressed labels.

"Am I getting the right thing? Like, I know it says, distilled, does it have to be a type of distilled? Could it be, you know, spring water? You know what I mean?"

"I'm taking a lot of urine tests....and just last time, when I was supposed to take the test, I realised I had no bottle and I couldn't get one from the hospital……. no one's keeping on top of I whether I got enough of my equipment or not …..it's just incredibly annoying and hard and something you don't want to also, like on top of everything else, you're also monitoring all the time and it's hard to keep track of all of those things"

"When there's no address label, like when you get your package, it's so frustrating because you're so concerned about whether you're sending to the right place"

What patients want from PCmS

Test administration and results

> “But a lot of times when you get instructions it may be very close to the stuff that you have, but maybe it's just looks a little different. They have different ridges or just something that you're like, is this the right thing?”

> “I've been sent a blood pressure monitor at home for a trial. I couldn't even get it on. You know, I consider myself to be relatively versed in these things and because the instructions didn't tell you how to turn it on, I couldn't turn it on.”

> “You can see when your test results is coming back and it's just very simple and very easy and accessible and I get an e-mail whenever I get a message from my doctor and the test results back...For me, that was just so such a nice way and it feel so easy for me to deal with.

> “I think that automatic is always better. It can be monitored more easily if it's via an app for professionals.”

Key Advice

Participants shared concerns about the safety and timeliness of their test results, highlighting the importance of receiving result quickly. They had questions over who is monitoring the results and what this means for on-going care and treatment plans. There’s also a need for tracking samples through the process and a preference for personalised updates to reassure that their samples are not with other patients or lost.

Participants approved of the current automatic and consistent glucose monitoring tools, sharing that this was a more convenient and easy way to manage their health. This was especially the case for patients where sampling is stressful and/or action needs to be taken quickly - regular monitoring with automatic feedback empowers patients to take more control over their health and lower the stress or trauma of regular testing.

There is need for clearer instructions. Incorporating demonstration videos and/or visual examples with no jargon or abbreviations was vital. It was also important that images match the supplies they have been provided. Although the information should be provided by an HCP, it can be more relatable if a patient is shown using the equipment.

What patients want from PCmS

Social and personal attributes

Key Advice

Participants highlighted the social stigma associated with needing to take samples in public, especially when needles are involved or if someone needs to use ‘disabled’ facilities.

There is also a concern for when people travel or go on holiday and need to take certain supplies on public transport or across borders.

Participants also highlighted the need for additional thinking and support for diverse patient groups. They gave some examples including, visually impaired people who may benefit from audio description, those with learning disabilities who may face challenges with emotional regulation or understanding written information, older people who are less comfortable with technology, those who live alone, or live rurally and those for whom English is not their first language. Its worth noting that all of these examples are not mutually exclusive, and we need to consider patients intersectionality.

“He uses the disabled toilets a lot and people comment on him coming out. You know, he looks like a young lad. He’s [does] parkrun, he's very fit…..It's really difficult, people are really judgmental”.

“I think there's a lot of people who don't speak English as their first language, particularly in minority communities”.

What patients want from PCmS

Improved interaction with healthcare systems

"Or an advocate that's willing to learn and ask those backup questions like…..especially if you're not feeling well, you don't necessarily think about that"

"[I never take it] that no news is good news because things get missed, I deal a lot with multidisciplinary teams, and it's a big problem. People do not talk to each other... I don't know that it should be necessarily, but it's my responsibility to connect all the dots"

Key Advice

Clear communication and interaction needs to occur between different doctors and clinics. Participants expressed frustration at being expected to navigate and manage multiple systems and individuals. When things go wrong, or samples go missing, it was described as being "up to the patient to solve the problem". Participants described needing to be astute and benefiting from a medical background or having someone like this to advocate on your behalf. Being unwell and receiving treatment takes its toll making it even harder to solve these problems.

Patients have a level of distrust in the accuracy of home tests and whether they do what they proclaim to do, for example, continuous glucose monitors from private companies. This is even more so for privately purchased test kits, such as the variety of COVID-19 test options, each with differing testing methods, instructions and potentially giving different results.

This should be of particular concern where waiting lists for treatment are getting longer or for health concerns where there is a social stigma attached. People may turn more and more to private suppliers where desperation can make people make risker choices when trying to get answers and manage their health better.

Discussion 4

Interacting with PCSIG in the future

Discussing how patients and carers would like to interact with PCSIG in the future and areas where collaboration may have the biggest impact.

Key themes: Interacting with PCSIG in the future

PATIENT POWER & INFLUENCE

PROMOTION & COLLABORATION

COST SAVINGS & PATIENT ADHERENCE

Interacting with PCSIG in the future

Patient power and influence

Key Advice

Patient stories and voices play an important role in communicating and understand the aims of the PSCISG.

Patient involvement can empower other patients to seek similar solutions in advocating for their own healthcare.

Helps build trust in other patients when it is known that something was developed or designed with patients.

> "When I know that whatever the information or resource or whatever it is that provided is communicated to me that a patient was involved in that......just having that sort of extra touch, I think just adds a certain specialty or like it just adds more care.
> I think as a patient and just knowing that someone else, even if it's not the same condition or not. But I know that it's someone that can relate to whatever it is that I'm experiencing."

Interacting with PCSIG in the future

Promotion and collaboration

Key Advice

Sharing information of activities such as this Ad board will help reach others and demonstrate the PCSIG values of patient centered thinking.

Patient Advocacy Groups (PAGs) or Patient Organisations are a great way to help spread the word, engage more opinions and experiences and change thinking. They are represented by advisory boards and are linked to not only patients but scientists, researchers and other professionals to reach wider networks.

Working with patients to design and test solutions will ensure that patients specific needs are addressed including lifestyle considerations, questions and concerns

> “Targeting these groups not only targets the patient community, it also informs the doctors that are providing these treatments as well. So I think targeting them is targeting a wide range of people.”

> “We care because we're usually all in this because we either have it or we're a caregiver or someone we love has it.”

Interacting with PCSIG in the future

Cost savings and patient adherence

"Actually, if you get that whole system right and then in the long run they're going to save money."

"It is very important that the patient population feel in control and specifically a sense of autonomy. You know, it really helps people to engage with services better. I've heard this from my mum, I've heard this from participants in my own study and I feel this in myself when I participate in studies."

Key Advice

Promote the savings made by reducing the likelihood of patients needing more intrusive health care in hospitals by empowering them to take care of their own health by regular monitoring and information.

Having treatments that are less stressful and easier for patients makes them more likely to adhere to treatment plans.

In summary

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