



The Importance of Lived Experience

A toolkit on approaching involvement in healthcare projects by the Mind & Body Programme at King's Health Partners



A few words from our experts

Charlie Costa

Expert by Experience

IMPHS

IMPHS has been extremely helpful in my battle with Schizoaffective Disorder, allowing me to focus and feel accepted by fellow Service users and the project team with no judgement and being able to collaborate with other people that can relate to what I'm going through. It felt like a safe zone, and I enjoy the moments I have with the full team. I also need to stress that I totally believe in the project too and believe it's going to help others like myself which makes it even more important to my personal views and is the perfect project and platform that allows to get involved in giving back to the community which gave a me an opportunity to live the life I do now.

Katherine Barrett

Expert by Experience

IMPHS

It was important to include service users in the development of the toolkit because we have a different perspective to the professionals. It was great to work on such an interesting project and I think the toolkit will be used by many people.



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”We need lived experience expertise to give context to everything we do”

Professor Fiona Gaughran

Lead Consultant Psychiatrist at South London and Maudsley NHS Foundation Trust and Professor of Physical Health & Clinical Therapeutics at the Institute of Psychiatry, Psychology & Neuroscience, King’s College London

Introduction

The purpose of this toolkit

When it comes to designing and evaluating services within healthcare, it is vital to consider the views of the people who the services are designed for as they offer a different perspective to staff, researchers and project teams. This toolkit shares the learning from the Integrating our Mental and Physical Healthcare Systems (IMPHS) project, formerly delivered by the Mind & Body Programme at King's Health Partners, on working with Experts by Experience.

What do we mean by Expert by Experience?

We will be using the term Expert by Experience throughout this booklet. The following definition is based on our experts' own experiences.

An Expert by Experience is someone who shares their knowledge based on their experiences, for example, for the purposes of service evaluation. They can provide feedback on project work based on their experience of using services which the research team may not otherwise have.

Having Experts by Experience can help to more effectively shape projects and by prioritising meaningful involvement, project teams can ensure their work more positively impacts on the services and people for whom they are intended to benefit.

What this toolkit contains

With our Experts by Experience, we have developed a series of key principles based on our learning of what worked well in the IMPHS project. This booklet contains the views of both the Experts by Experience and the project team on the benefits of including people with lived experience in project work, as well as practical examples of how we created good working relationships to benefit both the project and the experts involved.

Why a toolkit?

We recognise that there is not a one-size-fits-all approach to working with Experts by Experience. We felt that by developing key principles based on our learning and set them out in a toolkit, it may provide the flexibility for others to explore how they could adopt similar approaches in their project work too. We encourage this toolkit to be used as a guide to support project teams when exploring ways of working with Experts by Experience and certainly hope others will look to build upon it through their own work with Experts by Experience in the future.





Learning from the Integrating our Mental and Physical Healthcare Systems Project

Background

Integrating our Mental and Physical Healthcare Systems (IMPHS)

IMPHS was a 3-year funded project commissioned by the Maudsley Charity that ended in March 2023. The project was delivered by the Mind & Body Programme at King's Health Partners, hosted by South London and Maudsley NHS Foundation Trust in partnership with King's College London.

Original project aims

The IMPHS project sought to:

- Understand barriers that adults living with long-term mental illnesses may face when managing their physical healthcare.
- Test and evaluate interventions that could better facilitate integrated mental and physical healthcare in routine practice for patients accessing services both now and in the future.
- Work with Experts by Experience to co-produce and deliver projects.
- In doing so, the project aimed to develop a body of work that could be shared with healthcare staff, organisations, service users and carers to support high quality physical healthcare for adults with long-term mental health problems.

To find out more about the IMPHS project, download our portfolio [here](#).

Working with Experts by Experience

A commitment of the project was to champion the involvement of people with lived experience (known within the project as “Experts by Experience”), to ensure the voice of people living with a serious mental illness and associated physical health problems, and carers of people with those conditions were included in the development and delivery of the project.

Why we wanted to share our learning

At the end of the IMPHS project, we reflected on our approach to involving Experts by Experience in our projects and realised we may have some learning that other project teams could benefit from in their current and potentially future work.

Both the project team and our Experts by Experience felt that it was important to share what we have learned from working together on the IMPHS project and set out to create this toolkit together.

We hope you find this toolkit useful.





“The value of involvement from service users, contributes to the prevention of the development of echo chambers of professionals who are at risk of being caught up by their clinical perspectives. What we know is that engagement and relationship are central to behaviour change in a mental health setting. Therefore, the voice of the service users support the above effectively and reduces a limited perspective on what works.”

Helen Kelsall

Deputy Chief Nurse, South London and Maudsley NHS Foundation Trust



Our key principles of working with Experts by Experience

Reflections from the IMPHS project

Our key principles

Overview

We recognise that every project is different. However, we believe that healthcare projects are richer from including the voice of Experts by Experience to share their perspectives to ensure services do benefit the intended users. Throughout the IMPHS project, we received feedback that the Experts by Experience we worked with, liked the way we worked with them and so, with their encouragement and input, we decided to document what principles we had adopted or applied in practice to support authentic, effective and meaningful involvement across our projects.

Together with our Experts by Experience, we have co-developed the following principles of practice that we would recommend to others when considering ways to approach involvement in their projects:

Principle 1

Embedding the voice of lived experience into everything you do

Principle 3

Prioritising psychological safety and ways to engage meaningfully with your experts

Principle 2

Promoting an inclusive and collaborative approach to working with your experts

Principle 4

Championing opportunities for experts to continue sharing their experiences within and beyond the project

We outline in detail our reflections on each principle in the following pages, or you can jump straight to the principle of interest by selecting the link above.





Principle 1

Embedding the voice of lived experience into everything you do



What do we mean

Listening to the right voices

It is important to include the voice of experts when carrying out clinical and academic projects in a healthcare setting because the services that we are designing and evaluating are for the experts, therefore, their perspectives and opinions must be considered. No one knows the needs of our service users better than the service users themselves.

Why include Experts by Experience in your project?

Inviting Experts by Experience to join your project team can ensure project aims and outcomes are continually considered based on the service users for who they are intended to benefit. Involvement of experts can challenge project team's assumptions and provide real examples of services that work and do not work for them. Project teams are able to make meaningful changes to their project work based on the input they receive from experts with lived experience. This is especially true when a group of experts are included as it gives a more representative perspective and allows the output to benefit a larger group of people.

How our Experts by Experience felt about it

“We felt included in the conversation, rather than just being asked one-way questions, included in discussions and was encouraged to share thoughts and ideas in a co-productive manner.”

“It was beneficial that as an expert you could pick which specific aspect of the project you were involved in, which allowed you to choose areas that you had experience with and felt able to contribute to, rather than just being asked to comment on something that they had no experience of – it was more engaging that way.”

What did we do

Embedding the expert voice

In our project, we committed to thinking about different ways we could integrate the Expert by Experience voice, and at all levels of the project from design to decision-making to delivery. We recognised that the best way for us to facilitate project progress would be to involve the voices of people who knew best what it felt like to experience services.

As part of our commitment to embedding expert voices we:

- ❑ Worked with Experts by Experience to facilitate focus groups with other service users and carers to integrate their experiences into the project and give feedback on our suggested solutions.
- ❑ Made accommodations so that our experts could participate equally, just as other project members could do, on all aspects of the work and consistently consulted with them at all key project milestones.
- ❑ Paid our Experts by Experience for their time on the project, valuing their individual contributions to its success and outcomes.

Example: Service user and carer feedback workshops



We facilitated virtual and in-person workshops with service users and carers to invite their additional perspectives on findings from our project. Our experts worked closely with us to design those workshops, including the processes and materials used to promote them. Our experts also helped to co-facilitate the workshops across all platforms and importantly shared their experiences and views on what we had found and what we hoped to do by inviting wider perspectives through these forums. Our experts worked with us to collate the outputs from these workshops and feed it into the wider learning for the project.



“It has a more meaningful impact on the project because it's not only seen by an academic, it is also seen by someone who's actually gone through what is being discussed”

Anonymous

Expert by Experience
IMPHS Project

How did we do that

Being open during the involvement process

Expert by Experience involvement should be an inclusive process that elicits equal and open partnership between the project team and the Experts by Experience. We felt it was always important to invite honest and varied feedback throughout the project progress.

Making meetings accessible

We made reasonable adjustments where possible so that our experts were included and not disadvantaged. For example, by meeting with them before and after steering group meetings to explain the process and then answer questions about what had been discussed. If we were going to be asking our experts specific questions, we would share these ahead of the meetings so that they had time to prepare some notes if they wanted to.

Engaging experts at the right time

Our experts were asked to be involved as soon as was practicably possible. This meant that they were able to influence the design of the project and offer suggestions and feedback that could shape the projects to be as beneficial to service users as possible. At this point it is also helpful to have as many expert voices involved as possible, as each expert will have their own unique perspective and experiences.

How our Experts by Experience felt about it

"I think, they need to be aware of co-production. They need to understand it a bit before they go into trying to elicit service users views, because if there's a hierarchy and they're just imposing questions, it's not going to work. Especially if the questions are not something [experts] can answer."

"It's important to engage with service users or carers prior to getting everything documented down, it's important to know your audience... and to also know that your project will be benefiting the people you're trying to help and how it will benefit them... It's all about producing the best project for the most amount of people."



Principle 2

Promoting an inclusive and collaborative approach to working with your experts



What do we mean

Working inclusively and collaboratively

In the health and social care sector, we are fortunate to have passionate service users who are keen to share their experiences to improve services. Involving Experts by Experience to inform projects is important, but it is not enough to just have involvement, to really work collaboratively the Experts by Experience must feel that their contributions are seen as valuable. They must perceive that their perspectives are valued by other team members, and that there is sufficient space for them to make meaningful contributions.

To work inclusively, we wanted to provide equitable access to opportunities for Experts by Experience to be involved in these projects. We hoped that this would be reflected in the project environments we created so that they could safely contribute their ideas regularly and sustainably. We wanted our Experts by Experience to feel that they had effective and meaningful support to share their experiences and expertise in ways that worked best for them.

Going beyond consultation

Part of our approach in the IMPHS project was exploring the best way to involve Experts by Experience based on each workstream and what we were commissioned to deliver. Early in the project, we consulted with our commissioners, project leads, wider partners and stakeholders, and our population of interest to make sure we were considering whose voice we wanted to include and the best ways for us to bring them in. However, we wanted to go beyond traditional consultation and worked with our project team to expand the opportunity to include meaningful involvement and engagement of experts.

What did involvement and engagement mean to us?

To the IMPHS project team, involvement and engagement meant our Experts by Experience had a seat at the table alongside clinicians, academics and project managers. For us, it meant trying to involve our experts in every step of the project journey, and where possible providing an environment in which their views, ideas, and contributions could influence project deliverables and outcomes.

What did we do

We involved our Experts by Experience by:

- ❑ Offering membership to key project steering groups and associated meetings
- ❑ Inviting Experts by Experience to participate in detailed project work, including taking key roles on certain aspects of project deliverables e.g., participating in interview panels, being part of focus group development, commenting on study findings, supporting project report writing etc.
- ❑ Working with Experts by Experience to develop and co-deliver talks at workshops, events and presentations relating to the project

Example: IMPHS Project Steering Group



A quarterly working group that brought together the project delivery team, along with commissioners, partners and experts by experience to monitor progress and assure quality of the IMPHS project and its deliverables. Experts by experience received meeting papers a week in advance by post and email, were provided with a separate pre-meeting brief and debrief session to discuss the agenda and had a dedicated space on the agenda to share their views about anything discussed during the session.



“The experience has increased my confidence in the value of my perspective...every point I made or sentiment I gave was authentically acknowledged. A lot of our contributions also showed up in the resources and the work which made it even more clear that our voices were important and valued.”

Jake

**Expert by Experience
IMPHS Project**

How did we do that

- ❑ **Recruitment** - we recruited Experts by Experience to specific workstreams, in some cases we had specific criteria that they had to meet to be able to participate. This meant that Experts by Experience could be involved with work that reflected their own lived experience. This allowed them to feel that they could give meaningful feedback on things that they had actual experience with.
- ❑ **Accessibility** - most of our meetings were online due to the pandemic, but this ended up increasing accessibility for some Experts by Experience. It gave those who didn't feel confident joining in person the ability to join meetings from the comfort and safety of their own home.
- ❑ **Communication** - we created an open atmosphere in meetings so that our Experts by Experience would feel able to share their views and opinions. We did not treat it as a one-way exchange of information, we had open conversations where disagreeing was not seen as a bad thing, so long as it was approached respectfully.

Feedback from our Experts by Experience:

“It was natural, I felt it was a natural relationship. We were able to speak and be able to share and not feel judged and criticised, and always being supported and always having a line of communication open. That helped me and allowed me to engage and feel comfortable in engaging and sharing my experiences throughout the project”



Principle 3

Prioritising psychological safety
and ways to engage meaningfully
with your experts



What do we mean

How we approached safety

To prioritise psychological safety means to work with your Experts by Experience to create an atmosphere where each individual feels comfortable airing concerns without fear of negative repercussions. The emphasis should be on getting honest feedback rather than just positive feedback. We found by focusing on ways to ensure our experts felt safe in spaces we shared together and with other experts, we found it encouraged people to share thoughts and ideas openly.

As a team, we were honest with our experts about what could be changed and what couldn't within each of the projects. If there was an element that could not be changed, this was shared from the outset. This honesty from the project team helped to build an atmosphere of openness and transparency that proved to be vital for working effectively together. For example, this helped when discussing topics that could potentially be sensitive or triggering as it meant that the project team could check in with the experts to make sure they felt safe and comfortable, and that they felt that they could answer honestly.

Building relationships

Building effective working relationships can take time, so it is important to be mindful of that when starting out.

We found it helpful to:

- ❑ **Set and manage clear expectations** – both at the beginning of the project process and at the start of every new meeting – so that experts knew what we were expecting from them, what they could expect from us, and the other experts involved as well.
- ❑ **Offering a single point of contact for each Expert by Experience** – we made sure that every individual expert had a lead contact within the project team who they could contact if they had any questions or concerns throughout the project process. We found this helpful as a project team also to ensure that we could reflect offline as a group about the best ways to support our experts as individuals and as a collective on the project.

What did we do

Steps we took to ensure our experts felt safe and engaged

- ❑ Inviting interest to join the project through known involvement forums and care coordinators within the Trust we were working and having pre-meets with experts (and carers, or care coordinators) to talk about the project before they applied.
- ❑ Facilitating individual and group supervision for our experts, including providing additional resources for them to access additional support whilst working on the project.
- ❑ Providing training and skills support to our experts so they could develop personal and professional skills whilst working with us.
- ❑ Working flexibly with our experts to accommodate their individual needs whilst contributing to the project e.g., needing materials to be posted and meeting styles.
- ❑ Taking time over and above meetings to build authentic relationships with our experts on a 1-1 basis. Including showing genuine interest in their work/life outside of the project and inviting them to share that experience in other ways within our partnerships and programmes.

Example: Individual and group supervision



We wanted our experts to feel comfortable working with us and to do that we committed to provide regular and dedicated spaces for our experts to talk to us as a project team. At interview we asked our experts to share their preferences for how we would connect outside of project work, whether virtually 1-1, or in-person as a group, and worked to honour that wherever possible throughout the project. We strove for consistency and continuity in how we coordinated and facilitated those spaces to ensure our experts knew what to expect from us, and what we expected or needed from them.

How did we do that

Safe and conscientious practice with experts

In the context of our project, people with lived experience of a serious mental illness, may still be living their day-to-day lives managing that condition, and possibly other conditions as well. As a team we were conscious of how we were approaching conversations with our experts and what support we were putting in place to ensure they could participate comfortably in the project for an extended period of time.

Designing project work around experts

When starting project work, it is important to have considered the inclusion of Experts by Experience from the very beginning of the project. You need to consider whether you have considered accessibility for your experts, including factors like meeting length and location, the materials being shared and the language that is being used. If you are considering these factors from the offset, then it can make the project a much smoother and more enjoyable process for everyone involved.

Working responsively and reflexively

One factor that our experts told us helped them to be engaged with the project was the flexibility of being able to join meetings online. While this might not suit everyone, we recognised it allowed those who want to but could not attend in person, to join from the comfort of their own familiar surroundings and still be able to participate effectively in the project. The IMPHS project team allowed the experts to engage with the project in whichever way they felt most comfortable with no judgement and committed to support that engagement process as much as possible throughout the project.

Our experts also told us that they always felt included in the conversation, rather than just being asked one-way questions, for example, that they were included in discussions and were encouraged to share their thoughts and ideas in a collaborative manner. Our experts shared they found it beneficial that they could select which aspect of the project they were involved in, which allowed them to choose the areas that they had experience with and felt able to contribute to, rather than just being asked to comment on something that they had no experience of. As a team, we certainly found this approach supported our experts to participate in a meaningful way for them and for the projects they worked on.



“The value of a multidisciplinary working partnership is critical for delivering a patient centric care. I feel the strength of the IMPHS project was that in involved patients, caregivers, allied health professionals, psychiatrists and physicians.”

Dr Prashanth Reddy

Consultant Physician, King’s College Hospital



Principle 4

Championing opportunities for experts to share their experiences beyond the project



What do we mean

Being a champion of your experts' expertise

During the project we wanted to provide as many opportunities as possible for our experts to impart their knowledge to inform our work. This not only included sharing their experience to inform our project development, but also, sharing what they had learned whilst working with us outside of the project and to other networks and / or professionals. We wanted to work with our experts to equip them with information about what we were working on together and how, so that they could take it forward into other forums or projects where they were working to invite perspectives on our work, or to share that learning forward.

Ensuring a lasting legacy of work

Post-project we wanted to find a way to solidify the benefits and impact of working alongside Experts by Experience. We wanted to explore with our experts what 'legacy' they wanted to leave behind as part of the project.

We dedicated a small team to support a specific legacy project with our experts during the final months of the project.

Our legacy project

As part of our legacy project, we wanted our Experts by Experience input to help us:

- ❑ Co-develop an in-person showcase to share and invite reflections on the learning from IMPHS project.
- ❑ To contribute to the completion of our end of project learning booklet.
- ❑ To participate in our live webinar series to help us share learning from each individual project in the IMPHS portfolio.
- ❑ Work with us on a dedicated Expert by Experience toolkit, that would include a masterclass and sharing learning through the Mind & Body Improvement Network.

This principle sets out exactly how we approached legacy with our Experts by Experience and why we wanted to prioritise it as part of our project.

What did we do

What we did to champion expertise

- ❑ We asked for our Experts by Experience advice on where we could best promote our projects and get input from external stakeholders.
- ❑ We prepared materials for our experts to share within their own networks (for input or for information).
- ❑ We attended external forums that our experts were members of to help promote their involvement and share the impact this made to our projects.

What we did to invite learning during our legacy phase

- ❑ Facilitated individual lessons learned interviews with each Expert by Experience.
- ❑ Set up a legacy working group with all of our experts to invite their views about what should form part of the legacy.
- ❑ Invited our experts to co-design and participate in our End of Project Showcase Event to share their experiences about working on the project in a panel discussion.

Example: IMPHS End of Project Showcase Event 2023



Our experts worked closely with us in the co-design and co-delivery of our End of Project Showcase Event at the Ortus, London in 2023. They participated in presentations, joined a panel discussion to share their experiences, and co-led group work with our team alongside other event participants. They were integral to the events success and helped us to share our learning from across the life of the project. Faith and Charlie (pictured above) went on to share their stories in the Maudsley Charity Annual Report 2023.

How did we do that

We wanted to find different ways to involve our Experts by Experience and we found it helped to make sure we:

- ❑ **Provided ample opportunity** - to kick off our legacy work, we approached all Experts by Experience who had worked with us over the course of the project to see who wanted to join our legacy project team. Those that could not commit to meetings but wanted to be involved from a distance, joined our reference committee and would give feedback periodically throughout the project.
- ❑ **Were clear and consistent about what we were there to do** – the project had a clear purpose from the outset and every session was focused on working towards this with the group. We provided summaries for those that missed meetings as well.
- ❑ **Promoted personal ownership** – we wanted each Expert by Experience to feel a sense of ownership over what they were involved in and being able to contribute accordingly. We worked closely with each individual expert to make sure all involved were comfortable with how to participate in and promote the project.

How our Experts by Experience felt about it:

“The activities were thought through for maximum input... so, I think you know specifically what you wanted to get from us, and we were able to contribute.”

“All of my experience of working on IMPHS I’ve genuinely carried it forward to other projects... for example, when we worked with you and said we need a 10-minute break in meetings, you accommodated that, and I’ve taken that to other meetings now and it’s been so great.”

Added value

Really championing the voice of our experts allowed us to explore their knowledge as individuals outside of the project as well as whilst working with us. This added value to our project as our experts would invite external colleagues to input or would share our work with them. For example, when we delivered our webinar series, our experts shared the invitation across their networks to invite external organisations and professionals along to learn about the project, which helped build our project profile and ability to share impact.

Finally, our toolkit

Solidifying the legacy

Our commitment to ensuring everything we had learned from working with Experts by Experience remained beyond the life of IMPHS. We wanted to go a step further than just reflecting our learning in a report, we wanted to produce something useful that could be used or referenced time and time again by colleagues delivering clinical academic projects – hence the development of this toolkit.

What it involved

Creation of this toolkit has been a collaborative exercise delivered in partnership with our Experts by Experience. We wanted it to be useful and for it to include accessible tools for other projects to use in practice. Together the project included:

- ❑ Co-development of this toolkit (e-booklet)
- ❑ A masterclass (webinar)
- ❑ A video of our Experts by Experience

How our Experts by Experience felt about it

“I have found being involved very helpful...I felt safe and comfortable. The project is about health, so that's very important to me and to many others and if we can help each other [by sharing what we've learned] I think it has to help....it's great that we're producing a documentation that will live on beyond the project.”

What we hope it will go on to do

This toolkit is a way for us to share what we've learned together. Our hope is that others find it useful, but also, that they learn from it and adapt it to make it work for their Experts by Experience and their projects. We invite those that are interested in continuing to share their experiences to join our Mind & Body Improvement Network and be a part of our continued journey to improving how we work with people with lived experience, register at mindandbody@slam.nhs.uk.



“The value of involvement from Experts by Experience to IMPHS and similar projects is that we ground aims, design, processes and practice in the lived reality of everyday patients, carers and the wider public.... IMPHS was a shining example of education, commitment and human practice”

Dr Sarah Markham

Expert by Experience, IMPHS Project

Summary

- Inviting Experts by Experience to participate in your projects can truly ensure the work you are doing is reflective and responsive to the needs of people it is intended to help.
- Our work has led us to identify with our Experts by Experience the total value of lived experience and how to ensure as project teams we are doing the best we can to facilitate a meaningful process for Experts by Experience to work with us and contribute to our projects.
- This toolkit sets out our project specific learning and the key principles we found reflected our experience as a project team.
- We acknowledge that other project teams may encounter different ways of working on their projects and we encourage that learning to be continually shared to ensure knowledge and awareness of how to work in the best possible way with and alongside people with lived experience is achieved in everything we do and for the benefit of everyone we are here to support. If you would like to share your learning with us, you can see our full contact details [here](#).





Case studies

A selection of examples demonstrating why we wanted to work with Experts by Experience, how we involved them, and the difference that made to the delivery of our projects

➤ Health champions

A feasibility trial where health champions volunteered to support adults with serious mental illness develop personal health goals over a 9-month period.



The project

We undertook a pilot randomised controlled feasibility trial where participants were randomised to either receiving the Health Champion intervention (intervention group) or to have treatment as usual (control group). Health Champions were paired individually with someone using mental health services and supported them for nine months. This support was mainly once a week for one hour. The person was encouraged to let the Health Champion know what their physical health goals were so that they could support them with this.

Why Experts by Experience were recruited

We wanted people to work with us on the dissemination of the findings including taking part in webinars and developing an infographic.

The difference having Experts by Experience made to the project

There were four experts involved in the Health Champions dissemination work. The participants were asked to give feedback on the infographic which they all did either face-to-face or online. Two of the participants were also interviewed about their experiences of Health Champions for the webinar. You can watch the webinar [here](#).

"[Health Champions] is something that's really close to my heart, and I wouldn't be in the position I am in today if it wasn't for the people that cared. That's the most important part. I want to be that person that I needed when I was 16"

– Charlie, Expert by Experience who worked with us on Health Champions



**Mind
& Body**

KING'S
HEALTH
PARTNERS



➤ Community study

A service evaluation exploring barriers and facilitators that influence how physical healthcare is approached within South London and Maudsley NHS Foundation Trust Adult Community Mental Health Teams.



The project

This project set out to evaluate the attitudes and experiences of staff, service users and carers based within South London and Maudsley NHS Foundation Trust's adult community mental health services. We used a service evaluation framework to investigate these areas and consider common barriers and facilitators that impact on clinical practice and patient experience. The aim from this service evaluation, was to provide the Trust with insights to inform local decision-making and improve future routine practice regarding physical healthcare in community mental health settings.

Why Experts by Experience were recruited

We wanted people to work with us on the dissemination of the findings including taking part in webinars and developing an infographic.

The difference having Experts by Experience made to the project

We had two service users and 1 carer for an adult living with a serious mental illness consult with us on this project. Their involvement was invaluable to ensuring our approach to thinking about how services are provided in adult community mental health teams and potential barriers for staff, service users and carers in being able to share their experiences to support this project.

"Everything was run past us including details about how we would like to engage with the work. It felt as though every effort was made to include us and acquire our insights to support the project outcomes."

– Jake, Expert by Experience who worked with us on the community study



➤ Digital study

A mixed methods study that investigated what digital technology adults with SMI use to manage their physical health



The project

We wanted to find out which interventions people with serious mental illness are currently using to manage their physical health, assess the barriers and facilitators to use, and whether there is any tangible impact on people's physical health and health service use. We did this through an online survey, interviews and workshops.

Why Experts by Experience were recruited

We wanted to involve experts throughout the study and we recruited two Experts by Experience who worked with us throughout the project.

The difference having Experts by Experience made to the project

We met with the two Experts by Experience monthly throughout the project. They were involved in decision making at all stages of the project including designing the survey, developing interview questions, design of workshops, analysis and dissemination. They also attended the Research Ethics Committee with us where they were able to talk about their experience working with us and explain what we wanted to achieve with the project.

IMPHS project legacy

What we've done since the project ended

Thanks to the Maudsley Charity, we have been able to continue our commitment to sharing learning from IMPHS beyond project completion. We have done so through academic publications, webinars, presentations at conferences in the UK, Europe and Australia in 2023, award nominations and through continued collaboration with local partners through our Community of Practice work in South East London.

Find out more by reading our published learning booklet [here](#) or by visiting our website [here](#).

“IMPHS is great work – it is fantastic to see the emphasis on evaluation, sustainability, and lessons for implementation. We all know how hard this work is, and how much it matters”

Dr Mary Jane Docherty, Deputy Medical Director,
South London and Maudsley NHS Foundation Trust



IMPHS Team (let to right: Raymond McGrath, Dr Julie Williams and Gracie Tredget), attending the 2023 Maudsley Charity Grantee Project Showcase Event at the Ortus sharing the legacy of the IMPHS project with local partners and providers in South East London.

If you are interested in working with us

Our work on improving physical health outcomes for people living with serious mental illness continues in earnest. We're keen to close the mortality gap and play our part in supporting the system to address the inequalities faced by this vulnerable group in our population. Please contact our team at mindandbody@slam.nhs.uk for more information.

A note on the Maudsley Charity

Working closely with Experts by Experience was central to the success of the IMPHS project. We worked with our funder, Maudsley Charity, to be able to celebrate their involvement and share this with partners within the local system. Maudsley Charity provided dedicated funding for us to work with Experts by Experience on the project, continued to join our project steering group to learn about how their involvement was working throughout the life of the project, and funded a celebration event at the Ortus in Mar-23 where some of our experts participated in a panel interview to share their experiences on working on the project.



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Coordinated care

The Mind and Body Project team share information at an event at ORTUS

Integrating our Mental and Physical Healthcare Systems

Total funding awarded in 2018/19:

£1.7m

Treating body and mind for a better quality of life

Nearly half of people living with mental illness also have at least one long-term physical condition. Yet their physical health needs often go unmet because our health system is not set up to easily coordinate care of the whole person, mind and body. This contributes to the fact that people with severe long-term mental health conditions live 15-20 years less on average than those without.

In 2019, we funded a three-year project to identify, research and trial ways in which mental health services could better meet service users' physical health needs.

Integrating our Mental and Physical Healthcare Systems project (IMPHS), was run by King's Health Partners: a team made up of staff from South London and Maudsley NHS Foundation Trust, King's College London, King's College Hospital and Guy's and St Thomas'. Every activity was shaped by 'experts by experience' – people who live with, have lived through, or care for someone with mental illness – including some recruited into paid project roles.

The project led to a number of innovations in digital provision including the integration of mental and physical electronic health records, and the implementation of *Consultant Connect*, an application which enabled mental health teams to seek advice on management of patients' physical health, from senior doctors working in specialities like cardiology or cancer care in partner hospitals.

Over 60 different medical specialities were contacted by Trust staff via phone or app, and more than 70% of queries resulted in the service user receiving care for their physical health at the mental health facility, avoiding the need for hospital transfer. IMPHS' use of *Consultant Connect* was shortlisted for Best Mental Health Partnership with the NHS at the Health Service Journal Partnership Awards 2022.

IMPHS also trialed in-reach approaches – bringing experts onto mental health wards. A weekly Physical Health Clinic brought a consultant general physician into the Maudsley and Lambeth hospitals. The Clinic responded to more than 200 referrals, in 20% of which a hospital transfer was avoided by timely advice or a change to medication.

Another strand of the project brought in a pharmacist from King's College Hospital one day a week. They directly supported service users with medication issues and answered

queries from resident mental health pharmacists, who the project found lacked confidence in managing medications for physical health. A programme of webinars and guideline development worked to re-skill this group in common conditions such as diabetes and heart disease, as well as mental and physical health co-morbidities – where two distinct issues are present at the same time - like depression and inflammatory bowel disease.

A Health Champion scheme tested whether peer support could help people using Community Mental Health Services to improve their physical health. The Champions – volunteers with lived experience – encouraged service users to work towards their own physical health goals, such as being more physically active. Evaluation showed that the scheme was a positive experience for both parties and helped service users to succeed on their own terms.

Throughout the project, the focus was on making real and rapid change based on evidence. A number of initiatives tested during the project are now embedded in the way people are cared for across South London and Maudsley, and a programme of communications is sharing best practice with mental health services across the UK and beyond.

Charlie's story

Charlie is a service user and was an expert advisor on IMPHS Health Champions project



"I was diagnosed with schizoaffective disorder, and I have traits of epilepsy as well, which can be very bad. My care coordinator helped me get involved in the Health Champions network. Doing all this research, I've really enjoyed it. It's like a new calling. This is where I get passionate and where I know that I could make such a difference."

"I want to give back because I know what it was like for me as a youngster. I was so confused. I had a great mother but she didn't even know what was going on. Nobody knew. I'm a qualified electrical engineer and because of my illness, at my peak, I lost it all. And it was quite hard to accept at first, very hard. You know, everything's taken away from you like that."

"I've been able to have my life back again over the years. I've been humbled by seeing all the good work that so many people are doing – it's restored my faith in humanity a little bit as well, it's fantastic. I found myself really enjoying being able to help."



Faith's story

Faith is a carer for her adult son and was a member of the IMPHS steering group

"One of my sons had an episode of psychosis and was in the hospital some years ago, and one of the medications was causing high blood sugars. He said 'I'm not taking that anymore', but there wasn't that conversation to say, well, we are looking at your physical as well as your mental health."

"So to be given that chance to be a part of IMPHS and to be a part of the steering group has been really helpful. It has been a place where I have felt supported and confident to put my hand up and say 'Can we please think about the carer?' or 'Can you not use jargon and acronyms?'."

"If you've got an appointment and they start talking to you about metrics and whatever else, it's not going to help you. This is not just numbers; these are people behind the numbers. And it's all very well to say, oh, if you've got mental health problems you live so many years less. I mean, when I first heard that when my son was unwell, I was in tears. I was like, 'What can we do? How do we address that?'"

"It's actually the impact on somebody's life, on each individual life. It's not just that person, but it could be their husband, their wife, their children, relatives, friends. It impacts on everything."

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Maudsley Charity Annual Report 2022/23

Maudsley Charity Annual Report 2022/23



“The IMPHS project saved me... it helped me do a 360 turn, I lost everything through my illness and even though I was well I was left with a massive hole in my life... then I came across IMPHS...it opened the doors, and the team put me on other projects as well...always asking for my opinions and I didn't even realise I needed it so much. I finally found a purpose and felt massively fulfilled by it. Having a purpose, doing what I am passionate about, my life has become brilliant and that is because of the impact of IMPHS, it's been amazing.”

Charlie Costa

Former service user at South London and Maudsley and Expert by Experience, IMPHS Project



Useful resources

Exemplar project collaborating with Experts by Experience



The NIHR ARC South London

The NIHR ARC South London have a PPI team with the aim of bringing people with experience of using health and social care together with their researchers to help inform the ongoing research that they are doing. They have published resources to support involvement in research which can be found [here](#).

Their Implementation and Involvement Team produced an Involvement Strategy (March 2021), which outlines three key structures to support involvement:

- An involvement Advisory Group
- ARC South London Public Research Panel
- An Involvement Learning Network

You can find out more about getting involved [here](#).



A spotlight on the King's Health Partners Mind & Body Programme

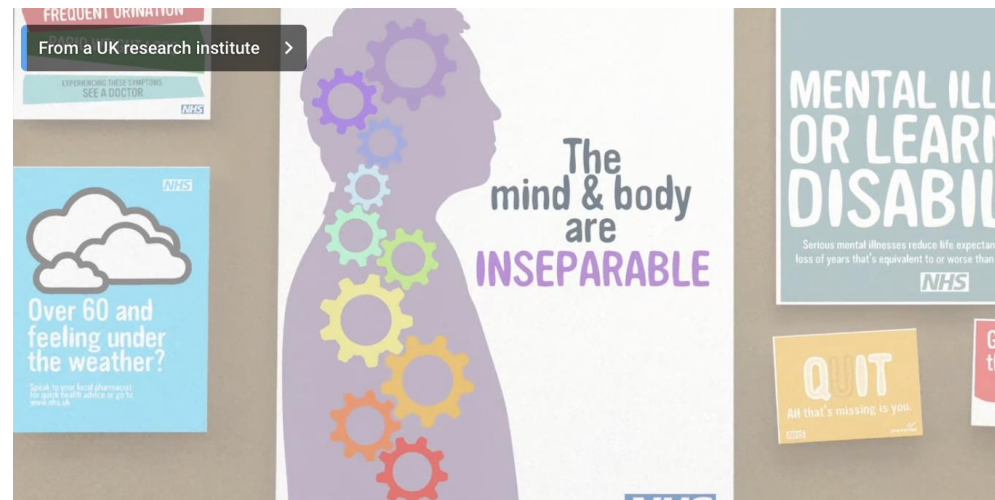
About us

The Mind & Body Programme at King's Health Partners believes that mental and physical health are inseparable. The programme is committed to championing excellence for complete mental and physical healthcare in a modern world through innovative projects that progress healthcare, healthcare improvement, education and research. Through doing so, the programme seeks to demonstrate the value of better joined up healthcare practice, pathways, and systems across mind and body care to achieve better health experiences and outcomes for patients.

To contact us see our full details on page 45.

The Mind & Body Programme is funded by partners at King's College London, King's College Hospital, Guy's and St Thomas' NHS Foundation Trust and South London and Maudsley NHS FT with support from The Health Foundation, Guy's and St Thomas' Charity, The Burdett Trust.

[Watch our short animation](#)



Join our Improvement Network

If you work in health and social care and are interested in different ways to better integrate mental and physical healthcare there's many others who are talking with us about what they would like to see improve within the system. Be a part of that journey with us and register to join our Improvement Network full of resources, forums and ways to network with professionals across South East London and beyond. Find out more by contacting our team at mindandbody@slam.nhs.uk.



Some useful resources on co-production

What is co-production?

The NIHR define Co-production in research as: an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start of the project, including the generation of knowledge.

Find out more

If you are interested in learning more about co-production specifically, here are some useful resources:

- NESTA and NEF have produced a co-production catalogue which can be found [here](#).
- A publication on co-production – a manifesto for growing the core economy, by Josh Ryan-Collins and Lucie Stephens can be found [here](#).
- A publication on the challenge of co-production – how equal partnerships between professionals and the public are crucial to improving public services, by David Boyle and Michael Harris can be found [here](#).





“It was so important to establishing the respectful culture of IMPHS to have experts by experience being valued and joining round the table as partners in design and delivery. Including this type of expertise helped remind everyone of the actual lived experience of services rather than the hypothetical experience. I believe that was part of helping create a culture that kept the work practically focused on impact and avoiding slipping into bureaucratic or siloed language and practices that can mask what is really being delivered and learned”

Alice Casey

Director of Programmes, Maudsley Charity

Acknowledgements

Contributors to this toolkit

This toolkit has been a collaboration between Katie Cooke, Gracie Tredget, Julie Williams, and four of our experts Katherine Barrett, Charlie Costa, Greta Gillett and Lana Samuels to ensure that the information included is a true reflection of their experience working with the IMPHS team and is intended to support other project teams to adopt positive and meaningful involvement of people with lived experience in their work. For more information about who has contributed to this booklet, contact our team at mindandbody@slam.nhs.uk.



Our partners

Thank you to King's Health Partners for its unwavering commitment to promoting integrating mind and body care, and the access this partnership has provided to be able to work collaboratively with organisations (King's Health Partners, Guy's and St Thomas' NHS FT, South London and Maudsley NHS FT and King's College London), clinical services, teams, professionals, and experts by experience that have contributed significantly to the overall quality and outcomes of the Integrating our Mental and Physical Healthcare Systems project.



Our funders

Thank you to the Maudsley Charity for its continued support in realising the legacy of the Integrating our Mental and Physical Healthcare Systems project. The Maudsley Charity works in partnership with South London and Maudsley NHS FT and the Institute of Psychiatry, Psychology and Neuroscience, King's College London to promote positive change in the world of mental health. They support innovation, research and service improvement, working with patients and families, clinical care teams, researchers and community organisations with a common goal of improving mental health.



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Contact us

If you're interested in learning more about the work we do in the Mind and Body Programme at King's Health Partners, please get in touch with us.

You can contact us by:



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mindandbody@slam.nhs.uk



www.kingshealthpartners.org/our-work/mind-and-body/

