

# patient advocacy

Learning from Mutographs

February 2023





We hope this report will be helpful for research teams who are at the start of their journey working with patient advocates. With the increasing number of opportunities for patients and members of the public to collaborate with researchers, it feels timely to reflect on what we have learned and gained over the past five years of the Mutographs project.

Maggie and Mimi have been key members of our team and Mutographs is richer in many ways for their contribution. My thanks go especially to them for giving so generously of their time, their insight and their expertise.

A handwritten signature in black ink, appearing to read 'Mike Stratton'.

**Professor Sir Mike Stratton, Director**  
Wellcome Sanger Institute

# Introduction

The **Mutographs** project is working across multiple research institutions internationally to discover how unusual patterns of mutation are induced by different cancer-causing events. The project has run for several years with funding from Cancer Research UK's **Cancer Grand Challenges** programme. For the past five years, two patient advocates (Mimi McCord and Maggie Blanks) have been a core part of the team, offering insight and challenge in support of the project and its researchers.

# Methodology

Over the summer of 2022, staff from **Wellcome Connecting Science** conducted a series of interviews with the patient advocates and several of the staff working on the programme to understand how the process of patient advocacy had worked, what had gone well and what might be improved in future patient involvement projects. This report summarises what we learned.

Visiting the Kimbilio hospice in Kenya, 2019. Credit: Kat Arney.



# Context

There is a growing field of practice involving patients and members of the public in health research. Many researchers (and funders of research) expect to involve the public and design their research to reflect this, although there is no broad consensus on how best to achieve this. Patients and many members of the public are interested in being involved, seeing their participation as a means to delivering improved patient experiences and potentially speeding up innovations in health and care. This field is broadly categorised as **Patient and Public Involvement and Engagement (PPI/E)**. At a basic level, this might include reviewing ethics applications or patient information documents, making suggestions for study protocols or helping to shape research questions.

Involving patients and the public in research is a key tool in preventing research from widening existing health inequalities. In particular, the involvement of patients and the public from communities traditionally marginalised in science and research may go some way to overcoming biases and systemic structural inequities which create those inequalities. Moreover, the involvement of diverse perspectives can challenge behaviours and cultural orthodoxies contributing to a more open, accessible and collaborative research culture and working environment.

However, the discovery science which often underpins health research can be harder for patients to access and understand than more 'patient facing' health research. The value of involvement is often more difficult to grasp for both patients and researchers. Sometimes, patient and researcher motivations, expectations and understanding of PPI may differ.

**Extensive literature** exists to support good practice in PPI - often focusing on building effective relationships, the 'buy in' of senior leadership and establishing good communication between researchers and patient/public participants. This report offers a case study which demonstrates the value of these principles - but also offers the 'human' perspective on PPI and shows how seemingly small factors can make a meaningful difference to research processes and potentially outcomes.

# Background

Maggie and Mimi have been involved in Mutographs for over five years. Their work has included travelling to see researchers and clinical teams in action in different global locations (Czech Republic, Kenya) as well as (pandemic related) virtual trips to Iran and Brazil meeting patients and researchers. They have attended numerous internal and external meetings along with the Mutographs team and have offered suggestions and observations at a number of points - particularly around how aspects of the research are communicated to patients, about public engagement and accessibility. They see themselves as lay experts, both are campaigners around cancer research with personal, lived experience of bereavement through cancer but they are not personally immersed in cancer research and see their role as bringing the human, non-scientist perspective to the wider Mutographs team.



1. Maggie and Mimi in Kenya, 2018. 2. Cancer awareness marigold, Czech Republic, 2019. 3. Cancer information leaflets at Masaryk Memorial Cancer Institute, Czech Republic, 2019. 4. Surgical equipment at Moi Teaching and Referral Hospital, Kenya, 2018. Credits: Kat Arney.

# The patient advocate perspective

Both Maggie and Mimi expressed how much they had personally learned through their involvement in Mutographs, about the scientific process and more generally. They were broadly positive about their experiences, particularly in terms of their personal development, and about the interactions with individual staff working on the programme. However, they also expressed frustration at how the role as patient advocates fitted into the wider programme. They had both enjoyed the 'in person' trips (especially the Kenyan trip). These had had a significant impact on their perspective as patient advocates and both felt it had deepened and broadened their sense of different patient experiences around the world. They had both found the introduction to the project challenging and felt they would have benefited from a clearer understanding and agreement around how their roles would work from the outset.

They also both noted that they were brought on to the project after many significant, relevant decisions had been made - limiting their ability to influence. To some extent, this may be an intractable issue as ethical consent and the regulatory framework for such a complex programme as Mutographs takes years to establish. However, it does perhaps point to the potential for patient voices to be incorporated more systematically into future programme planning and for patient advocates to become more involved in reviewing patient information sheets and wider communication for future programmes.

Mimi and Maggie noted that, at times in their involvement, communication had not always been as fluid as might have been desired but also acknowledged that the pandemic particularly affected their experience in this regard and severely limited the opportunities for more informal exchanges and relationship building. On balance they both indicated that their experiences had been much more positive than negative.



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*If I was asked to do it again,  
knowing what I know now,  
I would definitely say yes.*

Patient advocate

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# Principles

The **Health Research Authority** has detailed four principles for meaningful involvement of patients and the public in health and social care research:

**Principle 1: Involve the right people**

**Principle 2: Involve enough people**

**Principle 3: Involve those people enough**

**Principle 4: Describe how it helps**

Using these principles as a lens to review staff's reflections on the role of the patient advocates, it becomes clear that the Mutographs project adhered to most of these principles. It was clear from the interviews that all the researchers felt that Maggie and Mimi had been the right people. Several remarked on their commitment and application and genuinely felt that they had added significant value to the project.

## The researchers' perspectives

At points researchers noted they had been worried that Mimi and Maggie had been overburdened and that as (unpaid) volunteers they may have benefited from the role of advocate being more dispersed among a wider pool of participants. In relation to principle 3 (involving the advocates sufficiently), some of the researchers noted that they had been uncertain as to how to involve the patient advocates and there was a sense that at some points they had perhaps allowed Mimi and Maggie to become disengaged from the process. In relation to the fourth principle, all the staff we spoke to were glad of the opportunity to capture the benefit of Mimi and Maggie's involvement and told stories of contributions they had noted from their involvement.

We spoke to four members of the Mutographs team with different roles and levels of involvement with Maggie and Mimi. Their views largely overlapped with each other (and with Mimi and Maggie above). There was an acknowledgement from all of them that they had limited experience of PPI going into this project and that there had not been sufficient time invested in planning the roles and responsibilities. "We were feeling our way as we went along", remarked one while another acknowledged that "it [patient advocacy] was a bit of an add-on". There was also agreement that the project had benefited from the input of a member of Wellcome Connecting Science as a dedicated resource in support of the patient advocates. While this was not funded through the grant, it would be worth considering this in future budgeting perhaps equivalent to half a full time role for a project manager with experience in PPI/E. The role of a science communicator was also cited as having helped in 'translating' Mimi and Maggie's input.

Consistently, researchers commented on how the patient advocates input had been motivational - for them and for colleagues "it is important that scientists are reminded that data is from people". Several researchers agreed that greater prominence could have been given to the patient advocates in the structure of the Grand Challenge Teams (and indeed noted how this is being implemented in subsequent rounds of Cancer Grand Challenges funding). There was a sense that there could potentially have been greater impact if more space had been created for stories from patient advocates to be shared with staff working on the programme.

Several interviewees commented that they would have liked (a little) more support from the Cancer Grand Challenges secretariat, although it was also acknowledged that this was a new funding model and that a lot would be learnt through experience. They agreed with Mimi and Maggie that a wider network of support for patient advocates across the Cancer Grand Challenge programme would have been beneficial and efforts to establish this now are very welcome.

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***Science works this way but they had to learn that on the job.*****Researcher**

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There was an acknowledgement that interaction with the patient advocates had differed across the team of researchers and that more could have been done to foster opportunities for interaction (although Covid was clearly a significant factor in making this a challenge). Feelings were mixed about the use of Zoom - while informal chatting was reduced through fewer in person interactions, the ease of remote meetings made attendance easier to fit in (particularly for volunteer patient advocates with busy lives). The pandemic had also reinforced the idea that an international cohort of patient advocates would have been workable and would have generated a greater range of perspectives.



Mimi and Maggie visiting Mutographs researchers at Kings College London, 2018.

Researchers generally found that Maggie and Mimi’s involvement had encouraged them to use ‘plainer language’ and that this could be helpful for wider public engagement. “Talking to them has made the way I talk about science more accessible.” There was a feeling that more could have been put in place at an early stage to encourage the sense that there was no such thing as a silly question (“they were initially interested spectators”) and that a process could have been developed to encourage them to contribute as much as possible. In the last year or so, dedicated updates have been scheduled to brief the advocates on the progress of the science which have been mutually beneficial.

***It is great when people feel comfortable enough to say they don’t ‘get’ it.***

**Researcher**

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There was regret that “the science hadn’t co-operated” and that some of the things that had motivated Mimi and Maggie to be involved had simply not happened through the project. Had the research led to a clear insight with consequent public health recommendations, it was felt that the patient advocates would have been able to make a significant contribution. The unpredictability of research is something that scientists are perhaps more accustomed to than patient advocates (although both Maggie and Mimi have been involved in supporting research from many years – albeit not in roles quite like this) and this had presented challenges and occasional disappointment for Mimi and Maggie.

Researchers agreed that seeing the research process through Maggie and Mimi's eyes had reminded them quite how impressive and complex the international collaboration for the programme is. Researchers also commented on how heartening it was that Mimi and Maggie had noticed the integrity that lay at the centre of the research process.

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*Delivering this pipeline of samples properly and with integrity is a huge enterprise, it is easy to take it for granted and when others see it, you notice it more.*

Researcher

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Finally, the researchers acknowledged how much they had learned through the involvement of patient advocates in Mutographs.

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*They have helped me define what involvement should be, including where we didn't get it right.*

The Mutographs team at the WHO-International Agency for Research on Cancer in Lyon, 2019. Credit: IARC.

Researcher

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# Key points

## Clarity of the role

Both Mimi and Maggie felt that they were unprepared and ill briefed at the outset of the project and neither party had a clear sense of how they would be involved or how they could influence decisions. This has grown over time but has led to frustration and uncertainty at points over the years.

## Motivations

Mimi and Maggie were both motivated to be involved because they are keen to improve outcomes for patients and families with a cancer diagnosis. While this broad aspiration may be the same as that of scientists, the scientific process - which may not make linear progress to clear approaches that improve health outcomes - can be frustrating and can create a sense that this motivation is not being satisfied. Creating a shared understanding of how research on this scale works is essential. The unpredictable nature of research, the fact it is not linear and doesn't always lead to a 'cure' is essential in setting realistic agendas at the beginning of a process like this. It can be crucial in avoiding frustration and a sense of disappointment for advocates.

## Skills, support and representation

Some more formal processes could benefit future collaborations. It may not be necessary to create job descriptions and person specifications for patient advocates but due consideration of the range of skills and experiences that would benefit the programme would help in recruiting a diverse cohort of advocates. Training where appropriate would also ensure advocates were able to fully contribute and also get the most out of their role.

## Timing

The nature of complex scientific collaborations (especially internationally) mean some structures and processes are established many years in advance of patient involvement. The patient advocates both felt that they had joined the programme after decisions had been made, for example the wording for patient information sheets. The structure and the format for the programme was in place and they felt that they (or other patient/public perspectives) should have been engaged much earlier to help shape decisions and perhaps to also clarify the ongoing role of patient advocates. This is perhaps a wider consideration related to research culture and the role of the public in closer working with researchers more generally.

## Team working

While they had both really enjoyed meeting everyone in the team, Mimi and Maggie did not always feel that they were an integral part of the team. Agreeing ways of working at an early stage may have helped with this and clarified their involvement. There was a sense that some scientists and staff working on the programme were not always open to the contribution that Maggie and Mimi could offer. They both took the responsibility of their role very seriously and therefore it was all the more frustrating when they felt they were not fully involved.

## Hybrid

Using a mix of in person and online communication should be planned and put in place. Once time has been spent in person at the early stage of a programme, Zoom and other tools can be a useful tool enabling short and frequent interactions for participants.

## Personal development

Both Maggie and Mimi felt that they had learned a huge amount and had really enjoyed this aspect of the programme. Their knowledge of the science had expanded but also wider experiences (notably the Kenya trip) had had a significant personal impact on them. At the same time, they have become more confident as 'champions' of patient involvement in research and in turn this has enhanced and strengthened all the researchers' understanding of how patients can contribute to research.

## Impact

Mimi and Maggie were modest about the impact they have had on Mutographs but when pushed could describe a few occasions when they felt scientists had been given a fresh perspective through things they had raised or mentioned. For example, in sharing pictures and quotes from conversations they had had with other patients, they felt that some researchers were given renewed motivation and energy - a reminder of the human impact this research can have.

## Scope and limitations

Patient advocates have the potential to contribute to all aspects of the project, and their active involvement in basic scientific research should be encouraged and supported. In this way, patient advocacy can complement (and not replace) other types of **basic research**, exploring the needs, values and priorities of people and communities or the social, ethical, cultural, political, economic and historical contexts of human health and disease.

# Suggestions for future action

- A process of agreeing terms of reference with patient advocates would be useful for both parties to discuss the role, the motivations and minimum contributions. This could then be referred back to at regular intervals - giving an opportunity to monitor impact and maintain realistic expectations on advocates time and input.
- Alongside this, a defined process for recruitment, objectives and defined processes for ongoing communication would be helpful to put in place for future patient advocacy roles.
- For an international project such as Mutographs, it would seem appropriate to create an international cohort of advocates - with a broader range of experience and perspectives to offer the programme.
- In a large scale project such as this, particularly if there are multiple advocates, it would be advisable to recruit a role that supports the advocates and their activities (i.e. a role distinct from the scientific or programme manager roles)
- Patient involvement is clearly differently understood in different contexts (especially internationally) - some sharing and discussion of this across programmes would be very valuable and could be used as a tool to provide prompts and to inform future advocates before they interact internationally.
- There has not been a process of evaluating the impact of the patient advocates to date. This would likely have uncovered many examples of influence and change. Setting in place an effective evaluation process for future patient advocates would be helpful and would be a rewarding process for advocates, demonstrating the ongoing impact they were having and encouraging them to keep contributing.



Maggie and IARC scientist discussing the Mutographs project, Lyon, 2019.



Wellcome Sanger Institute scientist Sarah Moody showing the engagement activity 'Cancer Detectives', Lyon, 2019.

# A process for PPI

In future programmes at the Wellcome Sanger Institute, the following sequence of steps might be taken to meaningfully involve patient advocates.

1. **Consider** what is wanted from patient advocates. What is realistic - who might fit the bill, how long will they be involved, how many of them would help create an effective cohort?
2. **Scope** what other models are out there. Who is working with patients and what approach are they taking?
3. **Nominate** someone to lead this work and liaise with prospective advocates. Allocate resource to this role and to the advocates.
4. **Initiate** the activity, with a clear commitment from researchers and participants to a 'critical friend' relationship with a commitment to candour and responding to challenge.
5. **Establish** terms of engagement, the budget required, likely time commitment, etc.
6. **Agree** a process of communication and a (formal or informal) terms of reference.
7. **Discuss** motivations and the likely process. How will people respond when things don't go as planned? Ensure an understanding of how science research processes unfold.
8. **Inform** partners and external stakeholders of the role. Advocate for the advocates.
9. **Support** the advocacy process and the advocates themselves. Make space for advocates' input and foreground their involvement wherever possible.
10. **Commit** to working together, this may involve contracting/legal commitments.
11. **Document** the impact of the advocates, capturing as much informally as possible as well as more formal learning.
12. **Evaluate** the ongoing process, tweak and amend processes depending on what is working well (and not).
13. **Act** on feedback from the advocates and let them know what has changed as a result of their involvement.
14. **Thank** all involved for their commitment, ask for feedback and document ways of improving the process.
15. **Communicate** to the wider world the impact and importance of patient involvement.

**Thank you to everyone who contributed to this report.**

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