

# Wellcome Hub Evaluation

February 2021





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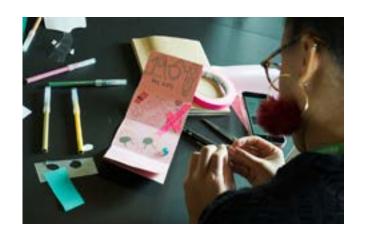
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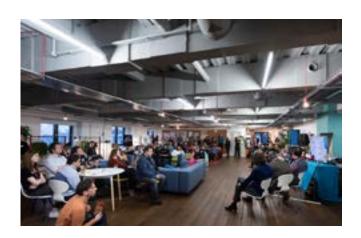
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# Introduction





#### Introduction

The Hub was set up in 2014 to provide a space within Wellcome that explores new ways of approaching health research. Residencies in the Hub run for two years and are provided a £1million grant together with use of a large physical space inside Wellcome to explore a health related topic.

Each residency is given freedom to define their research questions and methodologies. They are expected to use resources from across Wellcome, and engage with the public. The research team should be transdisciplinary, bringing together expertise from across fields such as academia, activism, arts and creative practice, clinical practice, and lived experience.

The aim for each residency is to conduct exciting and creative research that couldn't be conceived of or conducted within a traditional academic setting. They are encouraged to explore different forms of knowledge production including arts led approaches. By working in this way the residencies should create novel insights in their area of choice, and challenge the way research is understood at Wellcome and beyond.

This evaluation has been conducted to understand the impact that The Hub and its residencies are having, both inside and outside of Wellcome, and the degree to which it is challenging research norms. It has identified what is working well as well as opportunities for improvement. The evaluation was conducted by an independently appointed and neutral partner called Liminal which is a collective intelligence community focussed upon managing complexity and fostering collaboration.

The evaluation is based on a survey amongst 44 past and present residents with a good mix across the three residencies, 19 unsuccessful applicants from all years and 18 current applicants. These surveys were supported with 17 in-depth interviews that broke out as follows:

- 3x one-to-one interviews with senior Hub stakeholders
- 5x small group interviews (3-4 people) with Wellcome teams from across the Trust and Collection (all people in the teams had experience working with Hub residencies in some capacity)
- 1x one-to-one interview with a PI from a current applicant
- 3x one-to-one interviews with PIs from each residency
- 5x small group interviews (2-4 people) with members of each residency from a range of positions









#### Introduction

The three past residencies were:

### Hubbub 2014 - 2016

Hubbub investigated rest and its opposites, and the health implications of living in a fast moving modern society.

### Created Out of Mind 2016-2018

Created Out of Mind used creative arts approaches to explore, challenge and shape perceptions and understanding of dementias.



### Heart n Soul 2018-2021<sup>1</sup>

Heart n Soul, an arts based community organisation led by people with and without learning disabilities and autism, are exploring ideas like normality and the value of difference. In summary, we focussed our learning on three main areas, namely how:

- 1. The Hub ethos challenges research norms,
- 2. The Hub influences Wellcome's research and processes, and
- **3.** The Hub has wider impact outside Wellcome.

<sup>1</sup>Extended due to COVID19



# **Executive Summary**

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Wellcome Hub Evaluation | February, 2021







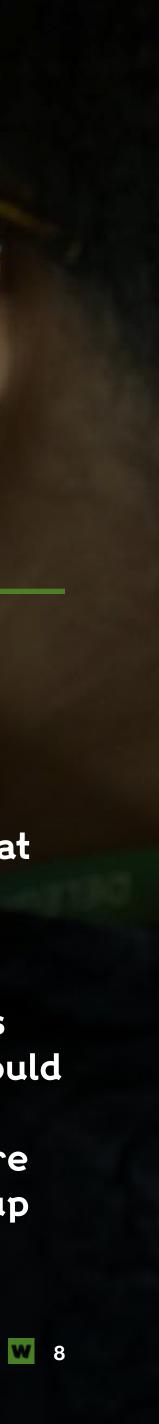
Firstly we learned that the Hub ethos challenges traditional research norms through three main ways:

- Freedom to explore During the application process residents propose a project outline and methodology, but once appointed they are encouraged to move beyond their original proposal as they develop their critical focus. This enables an exploratory approach to defining their questions and iterating their scope as they go - but it also adds some disruptive ambiguity to the process.
- Transdisciplinary working Residencies take the concept of transdisciplinary working further than most institutions. People from diverse academic and nonacademic backgrounds such as arts, science, media, healthcare, activism, communication etc work as equal partners to create new knowledge. This means each project within the residencies benefits from a diversity of thought from conception to execution.
- Challenging concepts of expertise Groups who have traditionally been under-resourced or their knowledge undervalued have had greater power and agency in Hub projects as research designers and co-researchers. Centering the expertise of those with lived experience has changed the research agenda and created greater societal influence.

Combined, these three factors reflect a challenge to traditional academic models of research and the metrics by which value and success are measured. This way of working means thinking deeply about the culture of the teams to foster collaboration and respect. Challenging research norms was a central reason it attracted interest from applicants. 95% said the opportunity to work in an experimental way was highly important to them in applying to do their project in The Hub.

"There's still huge hierarchies and implicit assumptions about what is more or less valued. So The Hub is asking some quite big existential questions to some degree about what research is and what constitutes quality. Really interesting."

"The opportunity for serendipity was very important. The people that I would have thought would be the most suitable collaborators on paper were not necessarily the people I ended up working with"



Secondly, The Hub influences Wellcome through the following three ways:

- Ways of working Many teams within Wellcome want to work in a more creative and collaborative way, but do not have a clear idea of best practice. There's an opportunity to learn from how the residents support collaboration across diverse teams but, relative to Wellcome, The Hub is very small - making it hard to have a wide-ranging impact.
- **Cultural** To challenge the intellectual hierarchies that exist within Wellcome by encouraging an intellectual shift in what knowledge is valued and increasing respect for different types of 'expertise'.
- **Procedural** The policies and processes at Wellcome are formed by cultural assumptions on who does academic research. As The Hub attracts people from very different backgrounds this has highlighted many shortcomings from the application to publishing stages - resulting in changes that make Wellcome a more accessible organisation to people from underrepresented backgrounds.

Whilst residents are keen to influence Wellcome and purposefully invited employees to certain events, it's a secondary objective behind conducting groundbreaking work. This challenge is mirrored from the Wellcome perspective, as the residents propose their own projects that don't necessarily overlap with Wellcome or departmental strategies, it's hard for Wellcome staff to see the relevance in engaging the residents. To increase The Hub's influence within Wellcome there needs to be greater advocacy alongside clearer avenues for why, when and how Wellcome staff can engage with it.

"They are using very specific production and participation techniques, different types of facilitation models, so that is technically of high interest to me, and it's good for my own personal development and I've been trying to share that with the rest of my position."

"I think just having them there, hearing that push back in their provocations to us, I think makes us as a community think; "What do we mean by good research?"









Lastly the short and long-term impacts of The Hub outside Wellcome were as follows:

- **Direct outcomes** As well as producing research outputs in the form of papers and articles, their work also sought to influence public perception, methodological innovation and directly informed new clinical practice. Created Out of Mind's Massive Open Online Course (MOOC), on how the arts can improve the experience of people living with dementia, was taken by almost 75,000 people - this demonstrates the practicality of a lot of the research to have a direct impact on people's behaviours and lives.
- **On residents themselves** Residents found it very fulfilling working in a collaborative environment alongside people from different backgrounds and perspectives. They leave The Hub with a greater appreciation for other ways of working and thinking that they seek to involve in their future career. For many of the residents working in The Hub led directly to work opportunities.

ideas progress later.

It's hard to evaluate how 'impactful' each of the residencies has been due to the diverse nature of the outputs, and the length of time it takes for some of them to bear fruit. The three residencies so far have all created different types of value/impact - one of the strengths of The Hub model is its versatility in supporting residencies achieve different types of goal. Across the three residencies to date, 76% of residents said their experience working in The Hub has a large impact on how they work or intend to work in the future.

Longer-term impact - A lot of the work and relationships developed within the residencies have continued to produce value much later, including academic outputs like books and articles, as well as cultural outputs such as The Dementia Choir which became a BBC documentary. To get the most from The Hub it's important for residents to develop an exit strategy - with closer support from Wellcome to help the

> "I just think of myself completely differently, the way I operate in the world is completely changed, to be honest, I'm actually much more, I feel much more integrated with different disciplines and academic disciplines of research than before."

> "I never really anticipated my work being socially important. And so that has been the biggest confidence boost for me, as people say 'you should build on that."







### In Summary

The Hub model has demonstrated that it can adapt to allow different residencies to pursue their own specific needs and objectives in a way that is right for them and undertake projects that would not be possible elsewhere. When the residents (or applicants) have encountered challenges with the Wellcome system there has been a genuine desire to change the way things are done - and this has benefitted Wellcome, modelling ways of working that have questioned exclusionary policies and practices.

It's hard to evaluate how 'impactful' each of the residencies has been due to the variety of their output. Whilst they have published fewer papers than would be expected for other grants, they have produced multiple outputs across other forms and platforms. contributed to promoting knowledge and understanding in other ways. In particular, they have been successful in using creative approaches to increase public engagement and understanding about their themes. Work from all of the residencies is either directly or indirectly leading to new papers and new initiatives now - long after they've finished. Methodologically they've also inspired others, inside and outside Wellcome, to work in different ways and deepen collaboration with lived experience.

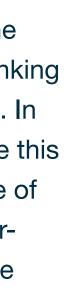
disruptive nature of the work.

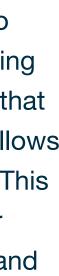
### However, working in this innovative way has also raised its own challenges. Leading such diverse teams can make it hard to meet everyone's expectations - so outside support and coaching was sometimes required, and all residents had to be comfortable with some level of compromise. Setting up a team to work cooperatively in this context required thought and planning from the start - however large teams and a short time frame meant this did not always run smoothly. The freedom the teams were given allowed them to be creative, but also at times meant they lacked

focus and a clear narrative behind their work. This ambiguity was also an issue for their collaborations with Wellcome departments, who did not know when, how or why to connect with residents - especially when their work didn't share strategic goals - raising the question about whether residencies should be aligned with specific Wellcome areas of interest. The application process is still very long and resource-intensive whilst being a 'winner-takes-all' format - which makes it risky for many groups to apply, potentially restricting the pool of applicants. Future development could see the main award complimented by smaller grants or spinoffs to increase the diversity of voices being heard and the

### The residencies have all shared a desire to challenge the status quo of academic research - in particular by rethinking how valuable knowledge is created and communicated. In The Hub, Wellcome have created an environment where this is possible. The credibility of Wellcome and the prestige of the building have been a resource for traditionally underrepresented groups of people to amplify their reach. The perceived neutrality of the space created a comfortable environment for people from all backgrounds, helping to overcome any sense of knowledge hierarchy and fostering effective collaboration. Having a transdisciplinary team that

co-creates the questions, not just the methodologies, allows for highly creative explorations of topics in novel ways. This makes it an exciting place to work for residents and, for many of them, has had a huge impact on their outlook and future careers.











"No other research funder would have supported a project as broad as Created out of Mind, or would have been happy with the risk of supporting work as exploratory and experimental. We learnt as much about process as about outcomes and Wellcome were comfortable with that. Wellcome's expertise and profile as both a medical research funder and a creative arts environment is unique and reflected the breadth of our project."

#### **Created Out of Mind**

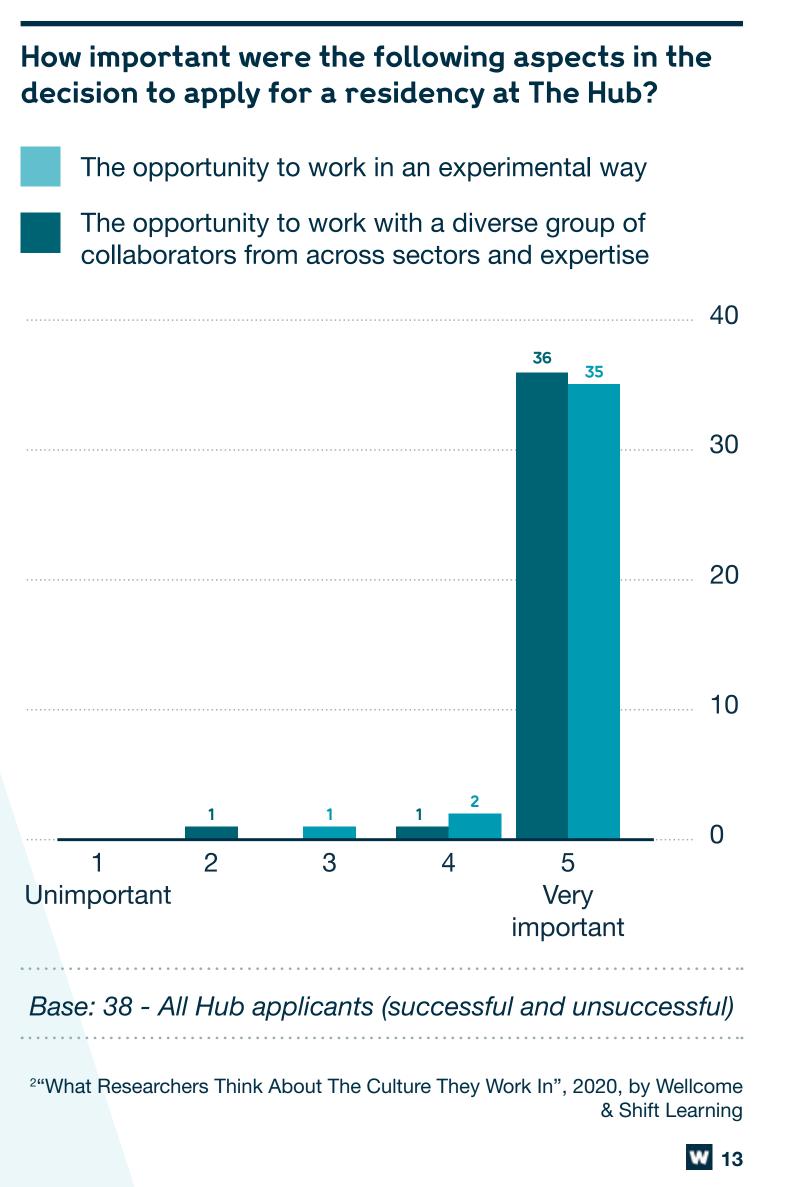
A recent report by Wellcome identified cultural and systematic issues within research that restrict its creativity and long-term relevance. Most research funding prioritises conventional methodologies with clearly defined short-term 'wins', over taking a chance on newer researchers or those proposing an experimental approach.

The Hub was established as a counter-weight to this culture. Its goal is to produce and communicate creative research that challenges assumptions about how research is done and pioneers new ways of working. It invites in residencies made up of diverse groups of backgrounds and skill sets, to challenge conventional notions of what expertise is, where it resides, and who decides what is important.

The idea of 'knowledge creation' is broadened from a narrow focus upon hypothesis driven research based on empirical observation to include artistic exploration and subjective experience.

This philosophy is central to the appeal of The Hub. The top two reasons for applying for a Hub residency were 'the opportunity to work in an experimental way' and 'The opportunity to work with a diverse group of collaborators from across sectors and expertise' - with over 95% saying both were 'highly important'. So it is essential that Wellcome provides the support and infrastructure for the residents to be truly creative in their approach.

The opportunity to work with a diverse group of collaborators from across sectors and expertise



There are three distinct ways The Hub encourages residents to challenge research norms:

## **1.1 Freedom to Explore**

Narrowness is a key theme identified in Wellcome's work on research culture. Firstly, narrow in relation to a focus on pre-defined objectives with an established methodology. Secondly, narrow in the way that success is judged typically by the number of papers published in respected journals. Both of these restrict exploration of new questions and creativity of approach.

The Hub set out a very different philosophy. Whilst applicants are required to pose research questions and methodologies, they are encouraged to revise and change those once the residency begins. The role of the application is to outline a broad area of enquiry that will be more fully explored as the project evolves. As remarked by a Senior Hub Panel Member; "the clearer about what you're trying to do the less interesting, by and large, what you are doing in culture is... there ought to be a spirit of a novel writer who doesn't quite know the shape or form of their final outcome." Most grants favour clarity and focus, whereas The Hub's philosophy values the opportunity in being open-ended. Whilst this can be conducive to more creative explorations of topics, it can also cause ambiguity and anxiety for residents throughout the process.

"Wellcome comes from a very scientific basis. It sees everything through scientific spectacles; you have a hypothesis, you test it and then you get an answer. Whereas we're simply the opposite. We don't have a hypothesis. We don't have a question. We've got an idea. But we don't have the question that we want to test, we have some thoughts about, 'wouldn't it be great to work with X, Y, and Z communities to forge something around an idea of rest let's say. I don't know what the answers coming out of that will be."

**Senior member of The Hub Selection Panel** 

The application stage for a residency is considered very thorough. There is a lengthy preliminary proposal which requires significant time and input, then a shortlist of applicants are provided a small amount of seed funding for a 9-month project development period where they further define their idea and team.

This culminates in an interview and final application document when the final residency is chosen. Currently it's a 'winner takes all' process where only one residency is selected.

During the application stage there is a perceived lack of clarity about what Wellcome are looking for. For instance, numerous applicants remarked that feedback from Wellcome on their applications was inconsistent leaving them unsure if they were doing the right thing. As the application process is a considerable amount of work (e.g. current applicants have been working on it for 18 months, albeit in part extended due to COVID) and the competitive nature, there's a fear and anxiety that they may not be taking the right approach. Whilst it is important the application process allows for a range of topics and methodologies, applicants would benefit from a more explicit and consistent communication of what Wellcome wants to achieve with The Hub.









"The biggest hindrance was probably a lack of clarity about what The Hub most wanted to fund. I came away thinking that it must have come down to topic, because the feedback on all other aspects of our plans was so positive. But that was very frustrating: we expended an extraordinary amount of collective effort on this process, and invested a lot of ... hope ... in how it would be to do the work. If someone had said at the beginning, 'Well, this is all great, but I'm not sure this is the right topic for us,' I wonder ... what might have we done instead with the momentum that our group had generated? It was wasted. Academic life is full of disappointments re: funding, but this one was \*really\* different."

**Unsuccessful shortlisted applicant** 

Once an applicant has been selected it is made clear that the residents have considerable freedom to deviate from their application. Several principal investigators recall having an early meeting with Wellcome where they were told they could put the application to one side and as one of the Heart n Soul researchers told us: "I think I read through it [the application document] once, maybe before my job interview, there was never the expectation from Wellcome or from our team to actually go back to that application."

At first this can create some anxiety - a disbelief at the level of freedom given - but Wellcome have stayed true to this philosophy. This level of trust allowed the residents to pursue the research they felt was important as their project evolved and this was felt to be a unique aspect of working with Wellcome. However, it also caused some uncertainty about what was expected of them as residents. In particular, trying to second-guess how much they should just get on with their research versus carefully documenting their process.

"So I felt a strong pressure to not only be doing the research, but commentating and sort of meta level doing research on how we were doing research."

**Created Out of Mind** 

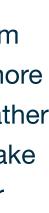
Freedom also means having the freedom to fail. As residents are experimenting on the nature of research itself, it is inevitable that some ideas or approaches won't work out. Being comfortable with this, and not feeling the pressure of writing papers for journals, was generally perceived to be freeing for residents. For instance this enabled Heart n Soul to entrust learning disabled people to take a leading role in much of the research and learn from their style and

approach - rather than adopting 'standard' experimentation approaches. However, this freedom should not mean disregarding insights from standard academic practice or a complete rejection of those approaches. There is a sense from within The Wellcome Hub that resident teams are strengthened when they remain open to feedback and consciously build on existing academic work.

The trust and freedom given to the residents allows them to work in a very organic way. They are able to spend more time exploring questions and themes as they emerge rather than being constrained by an original application. To make the most of this freedom, all the residencies planned for 'accidental discoveries' - opportunities for spontaneous conversations that could trigger ideas for further research. For instance Heart n Soul ran 'tea parties' and COoM ran many support groups for people living with dementia and their carers. At one of the COoM meetings a patient with a rare form of dementia remarked 'am I the right way up?' this triggered a series of research projects on balance and perception amongst people with a rare form of dementia. This was also important for the residents to have the freedom to truly explore their topic over the two years, but to really get value from this freedom, it was also essential that they consciously built in opportunities to be inspired to find the right questions.









"The opportunity for serendipity was very important. The people that I would have thought would be the most suitable collaborators on paper were not necessarily the people I ended up working with. It was only through the ongoing conversations that we had as part of Hubbub that the aspects of my own practice that were going to be the most productive to bring to the space became clear. Hearing the conversations between other collaborators, not just the people that you ended up working with, was also very inspiring."

Hubbub

Whilst this organic approach leads to better questions, it is also the cause of some disruptive ambiguity in the research process. The lack of clear and consistent goals means that the residencies can lack focus. This was exacerbated by large teams where different senior core team members could pursue their own interests independently from each other, as one principal investigator remarked "we set our net possibly too wide (because we could) - and should have imposed more discipline on ourselves". This also caused a specific, logistical issue for Heart n Soul who found that a lack of clarity made it hard to recruit collaborators or people with expertise because it wasn't clear what they'd actually be doing.

Overall, the freedom felt by the residents was an essential factor in their ability to be truly creative and experimental. However, greater clarity on Wellcome's expectations throughout the process from application to residency would increase confidence, and a more singular purpose from the residents themselves (even if it does evolve) would help to create a more coherent body of work and make collaborations easier to establish.



## **1.2 Transdisciplinary** Working

The term 'transdisciplinary' has become something of a buzzword in research over the last few years, often used to describe simple collaborations between two or more academic disciplines on a project. Many grants will seek to fund this type of work so it is not uncommon or especially challenging to see it being used in this context.

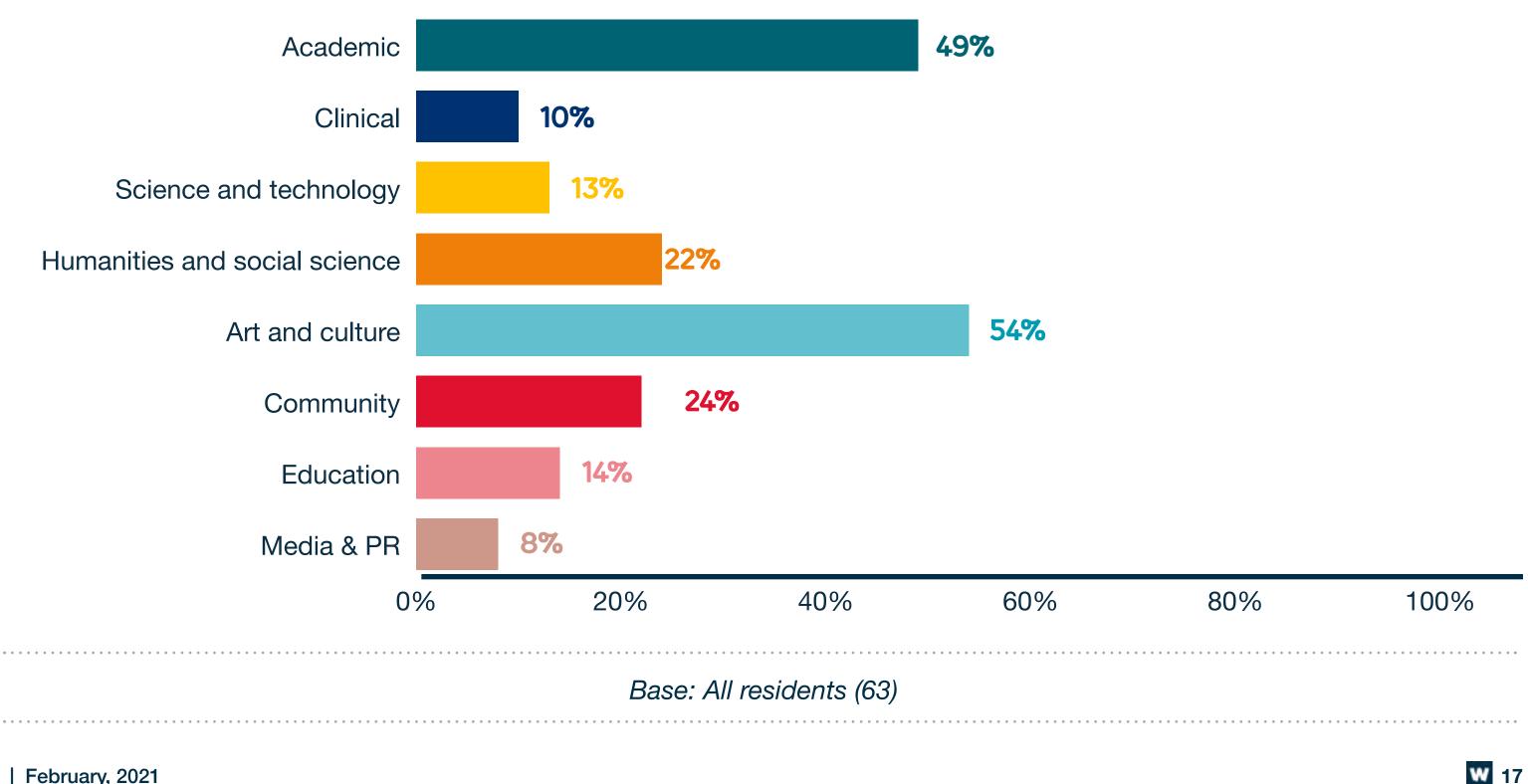
However, The Hub's take on transdisciplinarity takes this concept much further than most. It has been designed to bring together different forms of knowledge and expertise to create novel insights. So in each of the residencies there has been a mix of academic/research expertise (scientific and humanities / social science), lived experience, art/creative approaches and industry. It is founded on a belief that combining these diverse sources of knowledge will provide a broader perspective on the health issue they're addressing and lead to new ideas; together these disciplines will be more than the sum of their parts.

As the table below shows, only around half of the residents who completed the survey had an academic background. There was a genuine desire amongst all groups to combine different sources of knowledge and to take an approach to create different types of insight.

#### How would you describe your background prior to the residency/application? Please tick as many as apply

Humanities and social science

This means working together from the outset, rather than being led by one discipline and supported by another. This resulted in genuinely unique work that could not be reached without that form of transdisciplinary collaboration.





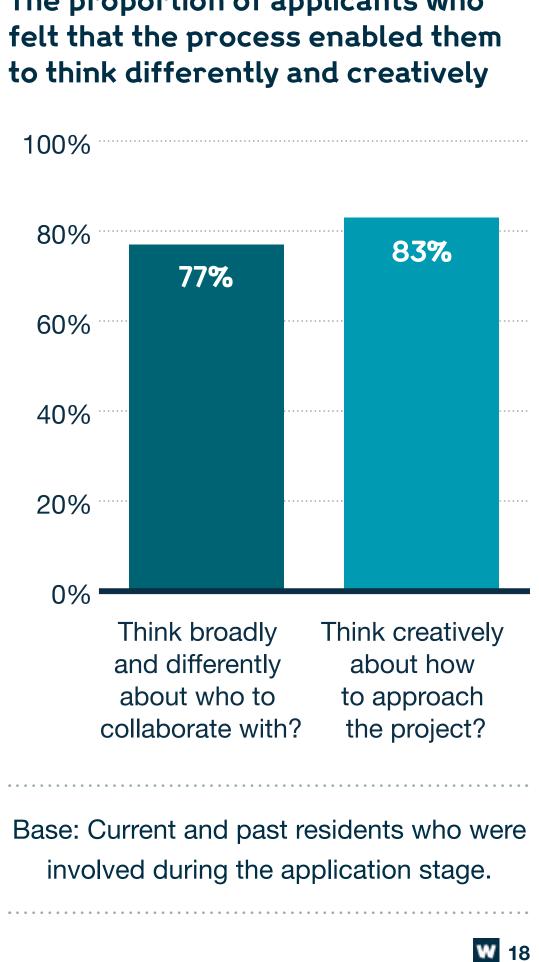
The Hub's philosophy rests on a bigger question about what constitutes good research. Whilst much Wellcomefunded research is conducted using established scientific methodologies and published in academic journals, The Hub equally values other forms of knowledge creation, for example, art and activism. Charlie Murphy, COoM's artist and co-director, worked with people living with dementia to develop artistic interpretations of metaphors that describe what dementia feels like. For instance, the below image was created with Jane Twigg and reflects how life events can have significant positive and negative impacts on her life.

The benefits of the transdisciplinary approach at The Hub begin in the application stage. Shortlisted applicants are given funding to develop their thinking and build a broad residency team. As the table below shows - 77% of residents found they were able to think more broadly about who to collaborate with during the application stage, and for 83% this was a creative experience. The application stage was a lot of work, and for the successful applicants in many ways it's where their residency really began.



← WINDBLOWN TREES 2017, cork print. Charlie Murphy/Created Out of Mind

## The proportion of applicants who



"It's exciting to be involved in research and working with such a broad spectrum of collaborators and partners. There's a beauty in the way we blend and bring different strengths to the table that has led me to a completely different understanding of just what might be possible!"

#### **Current Applicant**

For this way of working to succeed it is essential to have mutual respect for different styles of thinking and expertise. So once the residencies began there needed to be time spent discussing the culture of the team and how people would work together. As the table below shows a large majority of people felt that their knowledge and opinions were valued - and people in the team were open to different forms of knowledge (although within COoM over a third of respondents felt non-academic research was under-valued). Heart n Soul in particular placed a high degree of emphasis on openness and mutual respect amongst the team, encouraging conversation and visually communicating their beliefs and values on the walls.

Academic Experience Lived experience **Clinical experience** Creative approaches Non-academic / non-tra Your knowledge and op

### How valued do you feel the following sources of knowledge were/are during your residency?

	Hubbub	Created Out of Mind	Heart n Soul at the Hub
	100%	92%	94%
	70%	91%	100%
	60%	82%	75%
	100%	91%	100%
raditional approaches	89%	64%	100%
pinions	90%	73%	89%

Those answering 4 or 5 on a 5 point scale where 1 is 'undervalued' and 5 is 'highly valued'



**W** 19

The Hub is likely to be very different to how people have worked in the past, so it does put some people out of their comfort zone and requires a certain level of compromise. Inevitably, this way of working does not suit everyone and there were some instances of people leaving the residencies, or others staying but finding the experience stressful. It's very important for residencies to acknowledge this tension from the outset and to recognise that a lot of work and emotional labour is required to build a cohesive team. The teams may benefit from having some people with pre-existing transdisciplinary experience to support with communication and fostering collaboration.

"Talking to an artist and getting creative is very hard for me as a scientist, because I can't judge their ideas and they can't judge mine as well. It is even harder to talk on a nice level at all, because the intersection of our knowledge was so small."

Hubbub

This aspect of transdisciplinary working poses management issues for those leading the residencies, to both recruit people with a sufficiently adaptable mindset, and also to ensure there's a genuine culture of openness for constructive disagreement.

This is one area where The Hub team at Wellcome have developed essential skills - in recognising these tensions and their cause and providing appropriate support for managers and teams. This has involved coaching and team development sessions to support the residencies that was positively recognised by residents. The experimental nature of the residencies isn't just in how they design research projects, but also how they organise, collaborate and are led - and this will differ for each residency. There is a great potential to learn from the leadership experience in each of the residencies and to think through how it may be applicable more broadly.

"The aspect that kept pulling us back into the kind of academic sphere, more than anything else was the inevitable bureaucracy that has to go around doing scientific research with vulnerable adults with a condition that obviously is degenerative. And so, a lot of my role was trying to kind of introduce the artists into the idea that it has to be an ethical framework for work which is something they have never considered before, and some of them took it up really readily others, I think, found it a lot more of a challenge from a perspective kind of sometimes saw it as a bit of a top down impact partly about influencing their work which obviously is ordinarily really organic."

#### **Created Out of Mind**

The Hub is an experiment in transdisciplinary working. The ethos of drawing upon different sorts of expertise is central to its philosophy and way of working. Although it does cause some friction, overall it was found to be a highly rewarding way of working that genuinely helps to identify new approaches and ideas.











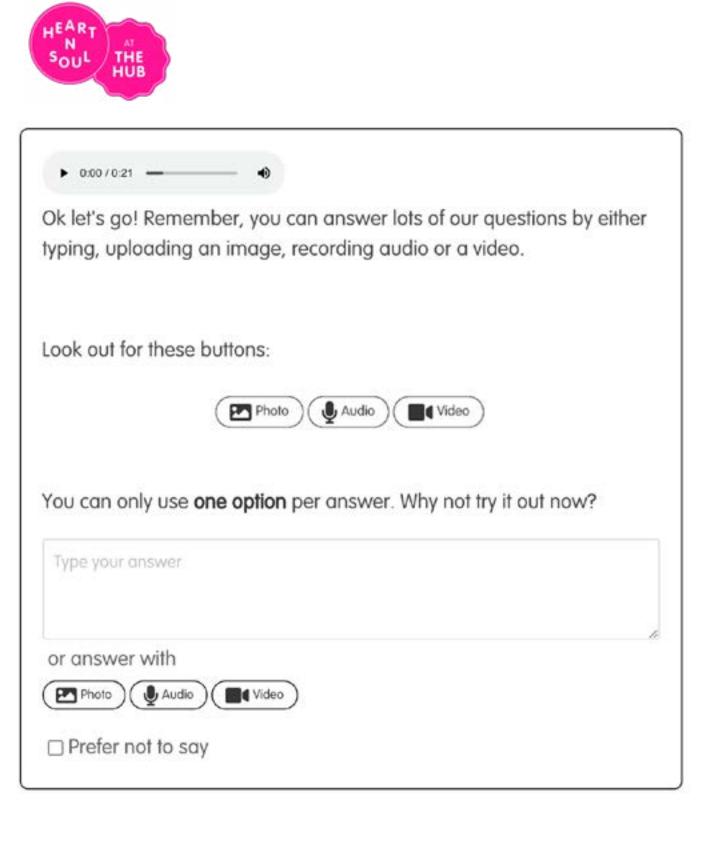
## **1.3 Challenging Concepts** of Expertise

Via its work on Research Culture, Wellcome is seeking to address the structural barriers that exist within academia that limit or disincentivise equitable and open participation in knowledge creation. The Hub is in a strong position to help Wellcome with this agenda. In particular it has provided opportunities for residents to challenge who dictates the research agenda by putting lived experience at the heart of the process. Heart n Soul in particular took a strong position, namely that people with learning disabilities and autism were often the subjects of research, but had little say in what was researched or how. By giving them more control, people with lived experience were able to prioritise the research objectives and adjust traditional research techniques - such as surveys - to be more accessible for people who aren't neurotypical (see image right). This work has gone on to have influence in broader society; for instance Transport for London have now taken the principles from this survey to inform how they communicate in their stations.

"I think there's this idea of knowledge in an academic context that doesn't resonate with the idea of knowledge in a lived experience context. You wouldn't use the word 'knowledge' to describe the experiences that people with learning disabilities or autistic people have without going down to the territory of 'experts by experience' and all these terms that academics come up with to try and justify the involvement of people in their research."

Heart n Soul

Normal surveys assume respondents are comfortable reading often complicated questions, or communicating their thoughts and opinions through written text. This image from Heart n Soul's survey shows how they provided options to hear or read each question, and to respond in different ways too. This makes the whole experience more accessible to a broader audience.







COoM had a similar insight to Heart n Soul when exploring how people living with dementia responded to questions in a standard 'quality of life' survey. One question asks about what mood the person is experiencing, but as one participant remarked: "which box should I tick if it's always changing?". Through experimental participatory methodologies, Hub residents have exposed underlying assumptions in academic research culture that limit its effectiveness in gathering representative, meaningful data. This subsequently contributes to the case for stronger collaboration with research 'subjects'.

This way of working can only come about by expanding on conventional notions of expertise by recognising that people with lived experience have incredible value to contribute as experts themselves. Whilst each residency incorporated lived experience in a different way, they all elevated the importance of listening to the needs, opinions and experiences of the people directly affected by the focus of the research, in creating and communicating impactful and important work. This challenges conventional research to co-create approaches with people who have lived experience and develop a stronger empathy of their experience.

One of the challenges of broadening meaningful involvement with research lies in its communication: from the use of academic language in papers to the inaccessibility of some exhibitions. This has put an onus on the residencies to put the needs of this audience at the centre of how they communicate. Heart n Soul introduced the Wellcome Collection to the idea of 'relaxed' events to make them more accessible to people who feel anxiety in noisy or crowded environments. People with lived experience have influenced how the residencies have communicated their research output and reports, as this quote from COoM explains. There are important lessons here for researchers and exhibition designers to think carefully about how to communicate their ideas to diverse audiences, to ensure the work can reach the people it is intended for.

"I got calls from people with dementia or carers that said "we don't like the way this is" or something. And it did change the way we did things and when I created the annual report we still shaped the framework, but then it was very much put around the quotes and their statements with people who had dementia. So it wasn't just the research and the work that changed, my communications changed because of it and it was kind of co-produced communications in the end as much as anything else."

**Created Out of Mind** 



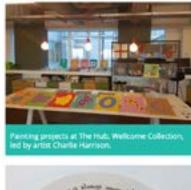






#### Created Out of Mind

is a team aiming to explore, challenge and shape perceptions and understanding of dementias through science and the creative arts.





Music is not medicine, nor drama a drug why should they be treated as such for those living with a dementia? Our research programme focuses on the power of the arts to communicate both the experience and biology of the dementias, and the value of in-the-moment experiences, not just long-term 'improvement

Our experimental approach incorporates he different motivations and languages of oners, researchers, policymakers, carers id people experiencing dementias. Achieving this as been made possible by talking, playing and working together as an interdisciplinary team ecisely the opportunity afforded to us by ellcome's Hub Award

Created Out of Mind is neither the beginnin for the end. It emerges from and owes a debt to the established fields of dementia and the arts, and creative aging. It has been and will continue to be shaped by our thousands of conversations with people living with different forms of dementia, and their many experiences, juestions and uncertainties. It hopes to spark new lines of evaluation, enquiry and education that will be useful in the years to come. If it succeeds in bringing closer those who speak of xperiences and experiments, then I for one shall be encouraged.

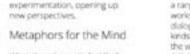
ebiestian Crutch, Director of Created Out of Mind and Neuropsychologist CL Dementia Research Centre

#### Language and Representation

How do we perceive dementia? How does language, science and culture affect representations of dementias, and the people who live with this condition?

We are exploring current representations — experimentation, opening up of dementias including those in the media, historical accounts, the science community and everyday language, with Metaphors for the Mind the hope of telling a new story enriched by personal, lived experiences.

Researchers are working with people living with dementias, carers and family experiences of dementia in persona embers, to respond to these accounts - public and scientific contexts. Differe through scientific analysis and creative expressions are unfolding through



What does dementia feel like? We are examining visual, textual & linguistic metaphors used to describe



a range of historic enquiries, creative workshops, visual experiments and alalogues with people living with differe kinds of dementias, their families and the wider public. Led by Charlie Murphy of Mind and Hannah Zeilig, Social Gerontologist, University of the Arts

"This is part of my ongoing conversation with Jane rigg through which we're or cycles of life and he huge impact that ferent conditions an lagnoses can have on your wellbeing. I made th age in response to Jane's hich made me acutely aware of how significant vents blow through with ooth positive and negativ consequences."

hanke Murphy, Artist and Co Directo rated Out of Mind

↑ Two pages from the Created Out of Mind Annual report

The diversity issue for research goes beyond the lived experience of neurodivergence. We also heard challenges from applicants about the demographic similarity of people within Wellcome - predominantly white and middle class. During the application stage this can feel exclusionary to people from different backgrounds because they're not represented. Outside of Wellcome too this experience

of 'otherness' - of people from different socio-economic groups - clearly exists. For instance Hubbub ran a project with a group of men from a hostel for the homeless culminating in them presenting at a Royal Geographical conference, however when they asked questions from one of the other speakers, they received a defensive response that illustrated the gap that exists:

"I think what that experience usefully exposed was that the very limited, and siloed and exclusive nature of many academic forum. Because of the inability of those other academics to engage with the critique posed by the men from the hostel, was really... you could have done a PhD just on that. Just on the language that they used on the way that they kind of closed ranks, many issues around class and professionalism, inclusion exclusion, whose points count in academia, were made there. And so, in that sense, I think it was also good that we all saw that, and it was disappointing that the conference organisers, and that session, didn't say, "right, let's, let's take this forward" because I think they just were too threatened."

Hubbub







This example, amongst others, highlights how often people with lived experience can be excluded from academic practice, but also the benefit to all when they are included. This is an area where The Hub makes a real difference. Each residency so far has invited people with lived experience into Wellcome where the prestige of the building and The Hub give a boost to people's sense of empowerment. This has the potential to change how they contribute during the sessions. Heart n Soul are usually based in Deptford and commented on the difference with events in Wellcome the space greatly enhanced the level of engagement and commitment given from attendees.

"The fact that they've got ownership of the space in that building reset people's attitude a bit. I think if we'd done it in Deptford people would have been doing what they usually do at Heart n Soul. So, strolling in and out of our staff office trying to make teas and get biscuits and stuff like that. But there was a level of professionalism that was expected of people. When they came in, they're not there to do art for the sake of doing art, which is what people are doing in Deptford a lot of the time."

Heart n Soul

Whilst this is an area The Hub has helped to challenge, there's still an opportunity for it to go further. The current application process reinforces traditional research hierarchies - the role of a few senior core team members works on the assumption of a top-down oriented team, rather than a more pluralistic one. This can then be reflected in the teams themselves once the residencies begin, although some of the shortlisted teams have worked hard to overturn this dynamic in the ways they have collaborated to develop their proposals - through adopting a disability justice model in one case. Whilst the principal investigator has to commit to a set number of days per week, the other senior people on the project may not be as present. This creates a gap between the senior team and the people who were there on a day to day basis that was the cause of some friction.

Every residency has interacted differently with lived experience. For Hubbub it was on a project by project basis, for COoM it was through regular interactions that inspired their research work, and for Heart n Soul it was where people with autism / learning difficulties were actual coresearchers who were able to set the research agenda.

So there's a breadth of ways the voices of lived experience can be incorporated into the residencies. This is helping to change the research agenda and different ways research's traditional hierarchy can be challenged.







## Chapter 2: The Relationship with Wellcome



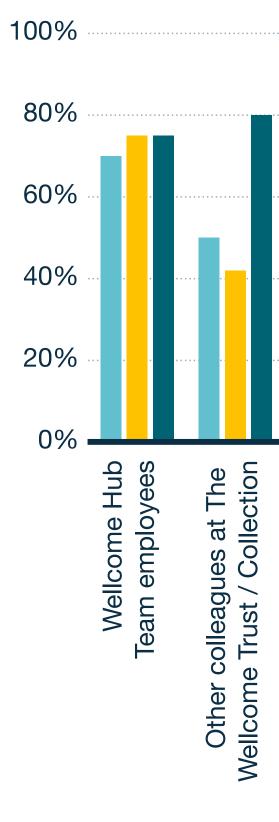


When we asked people from Wellcome whether The Hub had the potential to change the organisation, the answer was very positive. We discovered that there is a genuine need for change at Wellcome and The Hub can be a catalyst for it.

However, Wellcome is a large and complex organisation, so Wellcome staff were less positive about how much influence The Hub has actually had. For a relatively small grant, and only 2 years, it's hard for the residents to have a big impact on the whole organisation - but they do have a more targeted influence on certain teams and individuals.

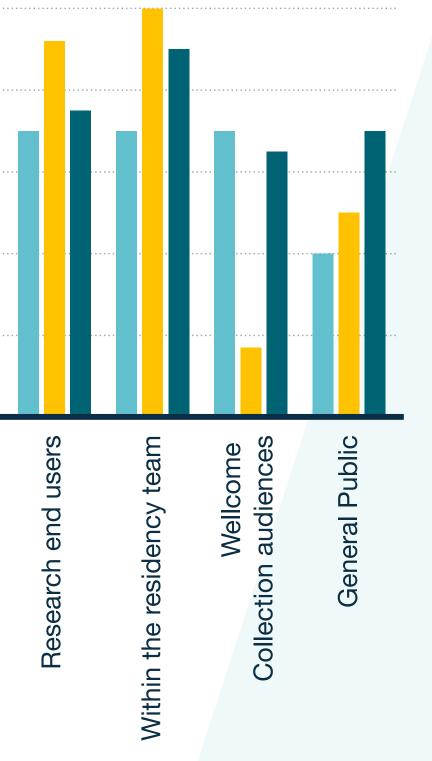
From the perspective of the residents - especially the first two - it felt as though there was a missed opportunity for more effective collaboration with Wellcome.

## residency achieve its goals?



Base: All residents, by residency. Top 2 box responses, where 1 is 'Very ineffective' and 5 is 'very effective'.



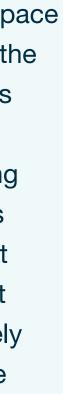


Unusually for a grant, The Hub team shared the same space with the residents so built up a strong relationship with the residents. They also attended the regular team meetings with the intention of helping rather than observing the residents. Their support has been instrumental in helping the residencies navigate the organisation. The residents recognised their role in making introductions to the right people across Wellcome and helping them get the most from Wellcome's resources. The Hub Team are effectively active collaborators on all stages of the project from the application onwards, providing critical feedback, networking guidance, and practical support informed by their own backgrounds across arts and research.

Hubbub (9)

Created Out of Mind (11)

Heart n Soul at the Hub (16)







## 2.1 Ways of Working

The Potential - Many teams within Wellcome want to work in a more creative and collaborative way, but do not have a clear idea of best practice. There's an opportunity to learn from how residents support collaboration to make this a more successful approach.

The Reality - Engagement between Hub residencies and teams in The Wellcome Collection and Trust varies greatly. There were examples of strong collaboration but there were also instances of initial enthusiasm waning and a sense of lost opportunity.

"There's often been a real kind of desire, particularly strong, I think, from the residents to make really good connections with the public programmes, teams, and the rest of The Wellcome Collection. And sometimes, and in some areas, that's been reciprocated, I think, not across all areas, but actually there have been some great outcomes and some great events and things that represent a kind of coming together. But also, I think there has been quite a lot of frustration, I think on both sides as to how surprisingly difficult it's been to make those connections and make that sort of joint activity possible."

**Wellcome Collection** 

### 2.1.1 Working with the Wellcome Trust

There were some very successful exchanges between people in The Hub and the Wellcome Trust. For people who truly bought into The Hub's philosophies of more open and transdisciplinary working, and engagement with different audiences, there was a lot to learn and a pride at having The Hub at Wellcome. These people chose to either attend Hub events or work with The Hub in different capacities, and to be an unofficial conduit with their departments.

"The Hub is almost like an experiment in itself. To me, the idea of bringing people together is just fascinating to watch how the ideas evolve and emerge over time, almost irrespective of what the end ideas are - the kind of evolution of it all, and how people start to come to that common language, and then generate whatever the end result might be as a consequence, I think is the bit that I really enjoy about The Hub."

**Humanities and Social Science Team** 

This brought tangible benefits to people in the Trust by developing their own capabilities - in particular related to collaboration tools and working with neurodiverse audiences.

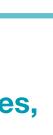
"[Heart n Soul are] using very specific coproduction techniques, participation techniques, different types of facilitation models, so that is technically of high interest to me, and that's why I've had some great conversations with the current residents and it's good for my own personal development and I've been trying to share that with the rest of my position because there is some overlap."

Humanities and Social Science, Wellcome

















The residents benefitted from these relationships too. They told us how they were supported by people in the communications team to develop effective strategies and to use their networks, or how people in the library went out of their way to support their research.

However, many people within the Trust do not have a strong understanding of what The Hub is or how they can meaningfully engage with it. Its position on the fifth floor leaves it feeling detached from the rest of Wellcome and they don't know what the procedure is to interact with people there.

"If you're not involved in the design of the call for applications and the assessment and all that kind of thing. It can be a bit murky, and I think it probably is, for a lot of Wellcome unclear about what The Hub is and what it's doing."

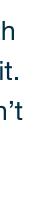
**Wellcome Collection** 

Some people within Wellcome experience The Hub's unique way of working a barrier. Words like 'wooly' and 'not robust' were used to describe some of the research that was being conducted. Judging the work on purely academic merits like this could be a valid critique of some projects (although certainly not all), but equally only looking at the value of the projects through this lens risks overlooking the broader implications and benefits of this way of working. As one collaborator commented:

"I did find it quite challenging to be perfectly honest. Having come from academic institutions where I felt like I had a fairly strong idea of what research was and the methodologies behind research, I found it quite hard... when working with the current residents, and they're talking about their projects being researched and it seems so far from the research that I was used to. There were times where I did almost worry about how that might be received, if we were going to be talking about it in that broader research landscape and with audiences that Wellcome traditionally engages with and I don't think I quite got to the bottom of that and figured it out. It was slightly challenging. I'd say... I actually moved off working with them after that."

Time is also an issue. People within the Trust are busy working on their own projects and towards their own departmental strategy so don't have time to engage with The Hub residents to understand how they could benefit. Even Wellcome people who are interested, feel they can't engage as much as they'd like due to busy-ness.

The Hub was set up to challenge academic norms, so it should not be surprising that some people within Wellcome find it hard to see the value in it that others do. However, more could be done to explain why The Hub exists, how the methodologies can inspire and inform researchers ultimately to help it feel more relevant to the experience of people across the Trust. They would benefit from a clearer understanding of what the residencies are doing, the benefits of getting involved and how and when to make that happen - essentially making it easier to learn from The Hub. The benefits of this interaction are two-way - the residencies too could benefit from more ideas and critique from people at Wellcome.











#### 2.1.2 Working with the Wellcome Collection

The Wellcome Collection has quite specific opportunities and barriers to more productive collaboration with The Hub.

They both share a strong commitment to engage and involve different publics in research. Given the collaborative nature of the residencies, and in particular their emphasis on the positioning and value of lived experience, there's a learning opportunity for both residents and Collection staff. For instance COoM ran training for Collection staff on dementia awareness that allowed them to think about how to design events for that group of people, and Heart n Soul's Chat Up events emphasised the importance of relaxed events for people with autism. The residents have helped the Wellcome Collection develop their competencies around neurodiversity and make it a more accessible place. "Heart n Soul work with neurodiverse artists and collaborators. And so they lead and put on the events and they work with this relaxed event environment, which is very specific to making all visitors feel very welcome, but especially those with neurodiverse challenges. And so that kind of whole format and style of event is something that we've worked from and work within, and we're building that practice into some of our event practices as well."

**Wellcome Collection** 

 $\rightarrow$  IMAGE: Photo taken from a Heart n Soul Chat Up event



#### Chapter 2: The Relationship with Wellcome



Despite the shared interests and successes between the residents and the Collection staff often the collaborations didn't come off. This is partly due to a clash between the spontaneity of the residents and the longer-term vision and planning required by the Collection. For large exhibitions the Collection have a two year lead time so are not considered for residencies, but even the timescale for smaller scale exhibits, experiments or interventions required a timeconsuming decision process. This was the cause of some frustration from the residents who want things to move at a faster pace. They would often find initial meetings felt positive, but then there was a lack of follow through.

"Even small things like could we put a little pod in the entrance lobby and use that as a good research recruitment tool, and a way of also engaging members of the public who have just wandered in and just want to take part in an experiment. In conversations like that there's lots of "Oh, I'll take that away and I'll speak to the people I need to speak to" then it just never happens.."

**Created Out of Mind** 

To forge a closer relationship between the Collection and the residencies means planning together earlier potentially before the residency officially starts - to fully think through and plan how the collaboration could best work. This is important to ensure that the projects develop with a realistic understanding of Collection programming in mind, and to ensure that, in turn, the Collection team have a true understanding of the potential creative offer of the new residency. This will be especially important for future residencies as the Collection develops a more strategic programme of activity across all its work. This emphasis on longer-term planning and coherent strategic direction is potentially less porous for the incoming residents, but more legible too; Wellcome Hub staff will play a key linking role.







## 2.2 Cultural

The Potential - To challenge the intellectual hierarchies that exist within Wellcome by encouraging an intellectual shift in what knowledge is and broadening the scope of what constitutes research expertise.

The Reality - The culture at Wellcome is heavily influenced by university / academic norms that can be experienced as exclusionary. This is reflected in the language used, the way applications are structured, who leads the research agenda, who the audience is etc. So Wellcome have a dedicated Diversity and Inclusion team working to build access and equity into their work. However, sometimes it is only through having more radical research models actually challenge the structures that unconsidered barriers are revealed. So each of the residencies has sought to challenge Wellcome's prevailing cultural narrative by bringing different audiences into the Collection and collaborating with diverse groups. Whilst it would be unfair to expect The Hub to completely change the culture of Wellcome, it has been the cause of some introspection and helped people within Wellcome start to question the status quo.

"Heart and Soul are challenging those implicit assumptions about who does research, what forms of knowledge could be valid in the research arena. And it is just getting people to challenge those implicit assumptions that they have about the kind of knowledge that is valued or devalued etc. So I think there is more work we can do on that, but I think just having them there, hearing that push back in their provocations to us, I think makes us as a community think; "What do we mean by good research?"

Mental Health, Wellcome

"I think they've [Heart n Soul] helped us a lot in the way that you know, on a daily basis these days, one realises that what one thought was a fairly open ended and accessible organisation, is structurally highly resistant to people who don't fit moulds breaking in. I don't think it is egregiously worse than many other organisations. But you know, maybe that's just a way of saying 'bloody hell. there's so many organisations that are so unaccessible'. And I think I think there is genuine eagerness and willingness to think about that issue and to address it, and maybe The Hub is a particularly good place, because Heart n Soul with a particular set of topics and identity characteristics help us think about disability, etc."

**Senior Hub Panel Member** 











## 2.3 Procedural

The Potential - The policies and processes at Wellcome were formed by cultural assumptions on who does academic research and who visits the Collection - there's an opportunity to update them to increase the diversity and accessibility of Wellcome.

The Reality - One area where The Hub's influence has been very visible is in processes and policies. As The Hub promotes a democratisation of research - encouraging people from different backgrounds to apply - it has regularly run up against unintentionally exclusionary policies or language. Each of the residencies, during the application and residency stages, have challenged Wellcome to become more accessible in small and big ways, as illustrated by these two examples:

The first residency, Hubbub (2012-2014), invited a large group of homeless men in for a workshop however they were unable to pay for their travel expenses in advance. Wellcome had to change its policy and pay the men upfront so they were able to attend the event.

The interview is an important aspect of the application process, but it didn't suit Heart n Soul who are more comfortable with less formal and more artistic methods. With The Hub team they rethought how this part of the application process could work to make it accessible for them. The lessons from this experience have been taken on by the grants team in their work around inclusive grant making.

"So we looked at the language that we were using and the accessibility of some of our documents, to try and make them a bit more friendly. And that also prompted us to look at our contracts more broadly, you know, and look at the way that we use gender identification and how we use language in our contracts to make that more plain speaking and more accessible. So that was definitely a positive from the interaction and experience that we had."

Wellcome Legal Team

There have also been times where Wellcome's processes have been more rigid and inflexible to the needs of the residents. Large organisations like Wellcome inevitably have a complicated structure of decision-making, that to small groups like the residents feel like unnecessary bureaucracy. This would raise issues when residents were looking for innovative ways to use the space or an area in the Wellcome Collection. Sometimes they were provided with specific reasons they couldn't do something - like a health and safety concern - other times requests just seemed to not get resolved.

"Some of our patients have a visual form of dementia. So we were interested that some of the Wellcome spaces are very gloomy and dark, and in impact on their experience with the gallery, and it took me about six months to arrange to speak to the two or three people needed to set up to open up the gallery on one of the days it's not open to the public, to try and test out this little procedure. And, and so small things like can we set a sensor to one at each end of the gallery just seems to be incredibly difficult and it never ends!"

**Created Out of Mind** 











## 2.4 Conclusion

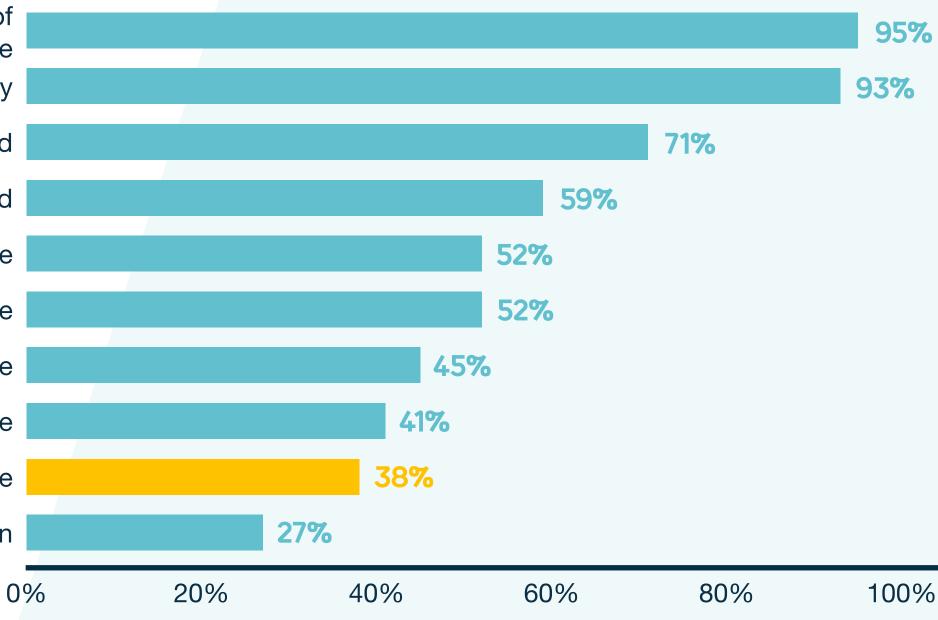
Currently The Hub's influence is targeted towards people within Wellcome who have a pro-active interest in what the residents are doing and by challenging the policies / processes that hold them back. Whilst there is a genuine desire from residents to influence Wellcome - and they did try to involve Wellcome people where possible - it's only a secondary objective relative to conducting experimental research in a topic they're passionate about, so not too much can be expected of them (see graph right).

### How important were the following aspects in the decision to apply for a residency at The Hub?

The opportunity to work with a diverse group of collaborators from across sectors and expertise The opportunity to work in an experimental way The amount of financial support provided The 22-month time period Being connected to a public space Access to Wellcome's expertise The physical space available Prestige associated with Wellcome Potential to influence Wellcome The central London location

% shows top-2-box on a 5-point scale where 1 = unimportant and 5 = Highly important Base: 56 - residents / past residents / current applicants involved in the application stage.

To elevate the residents' influence, the lead needs to be taken within Wellcome to communicate the perceived importance and relevance of their work and simplify the process for greater access and dialogue.



This could create interest from people at Wellcome and convert it into action, and remove the burden from the residents to be doing their own outreach.







# Chapter 3: Impact of The Hub Outside Wellcome





Chapter 3: Impact of The Hub Outside Wellcome

The impact of The Hub residencies over the last six years is difficult to objectively measure for three reasons:

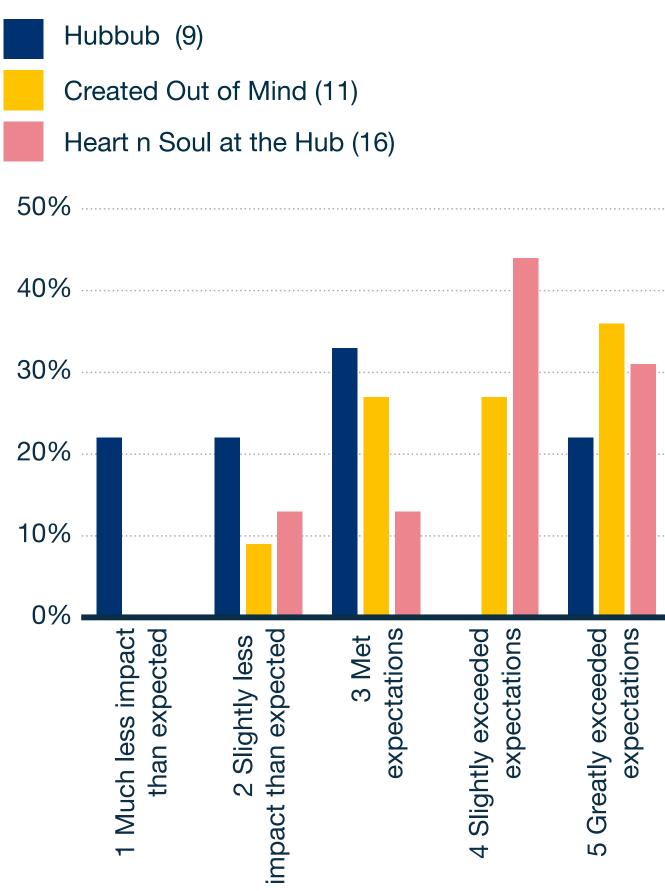
- 1. Varied nature of the output Whilst traditional academic output can be assessed by number of academic papers, quality of publications etc, these only constitute part of The Hub's output. Much of the value is in the community engagement, artwork, media coverage etc, all of which are harder to measure. Each residency had a unique mix of goals and methods, one of The Hub's strengths is that it doesn't tie itself to any one particular set of success criteria that applies equally to all residencies.
- 2. Long-term nature of benefits Many of the residencies' benefits are realised once they've finished in The Hub. For instance, "The Art of Rest", a book by Claudia Hammond influenced by her time in Hubbub, has only just been released four years after the end of the residency. Heart n Soul talk about their time in The Hub as a beginning rather than an end - so their success can only be fully judged by what happens next and they've already secured a £500,000 grant from The Health Foundation's Common Ambition Programme which is a strong start.

However, just because a conventional metric for measuring value can't be applied, it doesn't mean value isn't being delivered - and it is possible to apply more subjective reasoning in assessing The Hub's impact to date.

Firstly, according to the residents themselves, two of the three residencies have exceeded their expectations.

3. Research on research - An important part of The Hub's purpose is to explore alternative research methods and approaches. This work should therefore influence a wide variety of stakeholders; people within Wellcome, the broader research community and the residents themselves, but there aren't any currently agreed set of metrics to measure how much this influence has been achieved as a direct result of the residencies.

#### So far, has your research/practice had the level of impact you were initially planning for?



Base: All residents: Hubbub 9, COoM 11, HnS 16



W 35

Chapter 3: Impact of The Hub Outside Wellcome

Hubbub were least positive about their impact meeting expectations. By their own admission they tried to do too much and lacked the time and resource to complete it all fully. There was a sense that they would have been more successful with a more limited scope and greater project management support to free up the researchers from administrative tasks. They also faced various challenges post-residency. Due to the relationships between the team and the grant holding body, they were unable to develop their work in a cohesive way after the residency which limited their ability to create research momentum in their area. Their experience as the first residents, reinforces the importance of clear and achievable goals with the necessary planning and organisational support for researchers and more care around exit strategy.

"The worst: the amount of work to keep things running. Looking back I feel exhausted thinking about how much we tried to pack in -- too much; we were too anxious about what we felt we had to do in 22 months."

Hubbub

This paper has already discussed the impact of The Hub's influence on Wellcome, so this chapter will cover three other types of value it aims to provide on the residents, as a catalyst for more research and ideas, and on the residencies' direct output.



## **3.1 Impact On the Residents**

The Hub offers a way of working and collaborating with others which is vastly different from most other research or arts grants. 76% of residents said their experience working in The Hub has had a large impact on how they work or intend to work in the future, and 87% believe the relationships they formed are, or will be beneficial to them post-residency. They credit The Hub's philosophy with broadening how they see themselves and their work; notably the fact that they actually perceive themselves to have become more transdisciplinary.

"I just think of myself completely differently, the way I operate in the world is completely changed, to be honest, I'm actually much more, I feel much more integrated with different disciplines and academic disciplines of research than before."

Hubbub

People have articulated the benefits they received from their time in The Hub in three ways:

"I moved into the university Entrepreneurship team. I recognised that I really wanted a role where I was not limited by disciplines, and that I very much enjoy thinking outside the box. The experience also embedded in me the fact that I did not want to move into an academic team - I felt I had experienced too many ugly sides of it during my residency."

**Created Out of Mind** 

Clarity on personal direction - The experience of working amongst different disciplines on a health related challenge helped residents - especially more junior ones - develop a clearer sense of how they want to work. They were encouraged to think broader than individual disciplines and the opportunity to work creatively.

"I completed my PhD, did a 2-year postdoc, and then transitioned to a job in science communications. My experience at the hub definitely spurred my interest in knowledge translation and public engagement, and the experiences I gained in science communication though the hub have certainly been valuable on my CV."

#### Hubbub

**Directly led to new work opportunities** - Following the COoM residency many of the team were able to secure additional funding to continue working on projects that began in the residency. Heart n Soul are also building on their success in The Hub by applying for more grants which will provide more work for people in the team. The team from Hubbub used the experience and knowledge from their time in The Hub in their own academic jobs, but the residency itself provided fewer direct work opportunities. To make the most of this opportunity it is important for the residents to have a longer-term plan about how they would like to continue evolving their work after the residency. There's also an opportunity for Wellcome to think through how it can support residencies' exit planning - whether that's financial, use of their network, broader influence, internal opportunities etc.











"The project I completed with COOM led, almost directly, to further funding for similar projects. I feel quite strongly that had it not been for the Hub residency, I would not be doing a number of current projects."

**Created Out of Mind** 

Changed how they've approached their work - Many of the principles from The Hub - such as reimagining the role of publics in research and working across disciplines - were repurposed to tackle a variety of different health challenges in other contexts. This was important for people at all levels of seniority, giving them the appreciation and ability to work in different ways and to challenge the institutions they work in.

"I've always been into public engagement and how we create better relationships between researchers and publics and actually empower communities to be more active in research. And I think the way things were done in The Hub was quite different in the way they become collaborators. I think that way of doing things has influenced how I do my communications now. So I do work with infectious diseases... and I'm helping to develop strategies with different communities that not just involved them, but empowered the leaders of those communities to understand research and communicate themselves."

**Created Out of Mind** 

"I began teaching MA and BA students at UCL and my entire teaching methods are influenced by (and therefore involves the dissemination of) research by Hubbub collaborators. I also had an installation at the Barbican and the theme was influenced by Hubbub Research. This is about to be repeated and I'll be doing a workshop (drawn from my teaching) for the public in which Hubbub research will come into play. I also simply think of myself differently since Hubbub. If I find myself interested in something far removed from my core practice I no longer question it or worry that I'm getting distracted as I now have a far greater trust that something will come from it and that interdisciplinarity is a wonderful approach for me."

#### Hubbub

Without exception, no one we spoke to through the survey felt their experience in The Hub had influenced them negatively - the closest we heard was a concern they wouldn't be able to find anywhere like that to work again. From the feedback, it is clear that The Hub "alumni" will continue to be proponents of transdisciplinary working and will continue to influence how research is done and communicated long after they've left.







## **3.2 The Hub is a Catalyst**

The Hub is an accelerator - building on ideas, methodologies and questions that already exist and giving them oxygen to grow and develop long after the end of a residency. This idea is neatly summarised in Prof. Sebastian Crutch's (the COoM PI) introduction to COoM's first annual report:

"Created Out of Mind is neither the beginning nor the end. It emerges from and owes a debt to the established fields of dementia and the arts, and creative aging. It has been and will continue to be shaped by our thousands of conversations with people living with different forms of dementia, and their many experiences, questions and uncertainties. It hopes to spark new lines of evaluation, enquiry and education that will be useful in the years to come. If it succeeds in bringing closer those who speak of experiences and experiments, then I for one shall be encouraged."

This vision has been realised with a £3.15m grant from ESRC / NIHR to create an online support group for people with rare dementias run by Professor Crutch and supported by other members of the team.

Heart n Soul are a well established arts community organisation who seek to empower people with learning disabilities through art and performance. Despite not being researchers they wanted to use their residency to build on their work of challenging the public's relationship with learning disabilities. So they have been actively planning for the next steps and are applying for other grants to build on what has been established during the residency. This preparation and planning for the future gives them a strong opportunity to continue to build a strong legacy from their time at The Hub of which the Common Ambition grant is a positive first step.

"What we were embarking on is a 20 year process... That's what The Hub is offering something which really you can't do anywhere else, with the resources and the profile that Wellcome has, I can't think of anything else that is remotely similar."

Heart n Soul

Hubbub's experience is quite different however. Whilst individuals in the group have continued to use the research data - from the Rest Test for example - to produce interesting work, there wasn't such a clear plan for the residency to be a foundation for continued work. This represents one of the challenges for custom-made groups in The Hub - what happens next? Although people from the Hubbub team did apply for additional grants to continue to work, ultimately they were unsuccessful because they were a disparate group. For future residencies, it is important to think about this question from the start, if the residency team isn't going to stay together then how else is the work likely to continue and what is Wellcome's stake in that?

"I think that we kind of fell off a cliff edge at the end of the project, where we were, we were trying in various ways to get follow ups of funding but that was hampered by the fact we didn't have an institution."

Hubbub







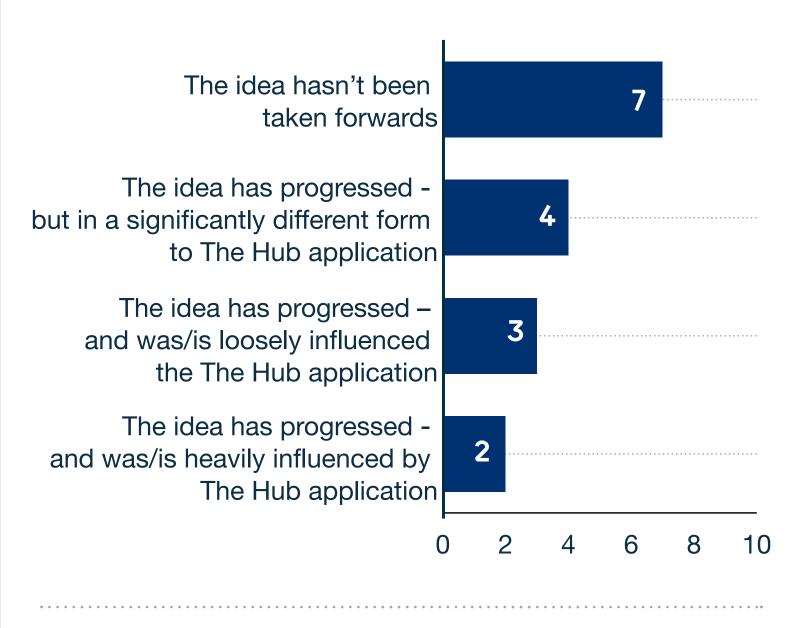






It's not only the residents who have the potential to take their ideas forwards, given the amount of development that occurs during the application process unsuccessful applicants also have an opportunity to continue their work elsewhere. However, as the table below shows, applicants tend to find it hard to repurpose their project outside of The Hub.

#### How has the idea from your application proceeded outside of The Hub?



The application stage involves a lot of work in developing a team and designing an approach that makes full use of Wellcome's resources. Whilst it is useful to have clarified the area they want to focus on, their application ends up being very specific to The Hub grant which makes it hard to transfer to other available grants. For example, they are encouraged to plan how they would use the space and make the most of Wellcome's expertise and resources that aren't available elsewhere. The emphasis on transdisciplinary working, and the mixing of the arts and academia, is also outside the mainstream grant economy. The effort of all this work only to be unsuccessful can also be draining, making the application-leads reluctant to continue pursuing it elsewhere. To many this seems like a waste of good thinking and effort - could there be other ways to help applicants develop their ideas outside the current Hub structure?

## the process."

**Unsuccessful applicant** 

Base: Unsuccessful residency applicants (16)

"There didn't seem anywhere else to progress the idea and the team were exhausted by

Overall, The Hub can be an effective catalyst for research and collaborations, but it's not inevitable. To make the most of The Hub experience requires early planning and being realistic about what can be achieved during the residency and what can be progressed after. For unsuccessful applicants The Hub can be the opposite of a catalyst, the amount of energy and commitment required in the application stage for such a novel grant scheme can be the end of the road for some ideas. There could be opportunities to innovate The Hub to look for ways to support smaller projects - perhaps even providing opportunities for unsuccessful applicants to progress part of their application.







# **3.3 The Direct Output of the Residencies**

The Hub is defined by its ability to support different types of research and output. This versatility can be thought of in three ways:

- A broad interpretation of knowledge creation -Knowledge creation can take many forms; artistic expression, scientific experimentation, methodological innovation, historical research, surveys, open conversation etc. Knowledge is also created through the experience of conducting research - learning what works and what doesn't. In particular, what research processes can be learnt or adapted?
- A range of intended audiences Residents had a range of different audiences - including academics, different publics, cultural sector, policy makers, people with lived experience and clinicians
- Different types of communication Beyond traditional papers and books, residents have been creative in how they've engaged audiences with their work through innovative and interactive exhibitions, talks, TV and radio, workshops, art and digital output.

Each residency has addressed a different mix of the above factors based on the expertise they have in the group and the ambitions of the team. According to our survey, 80% of respondents said they couldn't have achieved their research goals without The Hub and a further 14% were not sure. Wellcome has created the environment and support structure to help the residencies achieve these disparate objectives. Wellcome's prestige also played an important role in enhancing the credibility of the work and giving it greater reach to a broader audience. Over 90% of residents believe Wellcome's prestige was an important factor in helping them support their goals:

It's not in the scope of this paper to judge the size of impact of each individual residency, but we can demonstrate that The Hub provides the opportunity and platform for residents to achieve these different outcomes. Below we look at the impact of their work in three important areas: Communication and engagement, Research on Research and Knowledge Creation. How important is/was the the prestige associated with Wellcome in helping the residency achieve it's goals in The Hub?

1 - Unimportant	0%
2	2%
3	2%
4	32%
5 - Very important	59%
Don't know / not applicable	5%

Base: All residents (44)



A key goal for all the residencies has been engaging publics in the issue they're addressing and they all identified creative ways of doing this. COoM's work on the benefits of singing for dementia patients led to a subsequent 2-part TV documentary "Our Dementia Choir' amongst other TV and radio appearances throughout the residency. They also developed a Massive Open Online Course (MOOC) on how to use the arts to improve the experiences of people living with dementia - which almost 75,000 people have enrolled on.

Hubbub conducted the world's largest survey on rest ("The Rest Test") with 18,000 respondents and a supporting series of programs on Radio 4 exposing a large audience to this work. This approach has inspired replica projects run by Wellcome outside The Hub on Ioneliness and touch. It also provided a rich source of data, which in turn has inspired numerous papers and contributed to a book of collected lessons about rest based on their work in The Hub ("The Restless Compendium: Interdisciplinary Investigation of Rest and its Opposites", Palgrave Macmillan, 2016).

Both Hubbub and Created Out of Mind were helped in this by including public figures in their core team (Claudia Hammond and Philip Ball respectively) - this helped them gain greater traction with broadcasters.

The opportunity provided by the grant allows the residents to explore initiatives such as these, and importantly allows them to combine research with public engagement.

The Hub and the residencies themselves are in a sense a meta-experiment to identify new and better ways of working. This work has a broad applicability - not only for transdisciplinary teams but there are also insights for more conventional academic researchers too - both inside and outside Wellcome.

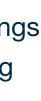
Heart n Soul sought to make the survey format more accessible to a neuro-diverse audience. The survey they designed allowed respondents to either read or hear the questions, and gave them a range of options on how they would like to respond. The COoM team also challenged the conventional Quality of Life survey - demonstrating that some of the questions were unanswerable for someone living with a dementia. By using lived experience to critique commonly accepted ways of working the residencies are able to innovate methodologically and improve how research is conducted more broadly. This demonstrates the potential for their work to influence more conventional academic teams, not just transdisciplinary ones, to work in a more equitable way.

COoM spent time consciously recording the experience of transdisciplinary research. The Diary Room experiment invited research collaborators to verbally respond to questions at randomly selected moments throughout the day. This approach allowed them to identify the little things that influence what people do and how they feel working in this way. Many of their projects involved bringing arts into hospitals (including one project where they played music to people with advanced dementia in care homes) doing this type of project poses administrative challenges of how to get it done. By pioneering with these projects they have uncovered insights into ways of working that can be used as best practice for other researchers - whether transdisciplinary or not.

"We've had a number of people since then, either through Wellcome or UCL, hearing that we've got something over the line and people have been in touch with me about coming to see all of the [ethical framework] documents - can I advise them about different ways of going about it."

**Created Out of Mind** 















"The projects which I initiated and led at The Hub have since been further explored over a year-long public engagement tour and are leading to further novel social science methods and new research. Some of the methods, approaches and understanding shaped through the residency will I believe continue to have a lasting impact of research in both artistic and scientific sectors."

**Created Out of Mind** 

The Hub is defined by its broad interpretation of knowledge creation. It is notable how creative the residencies have been in combining art and science to create truly novel approaches to knowledge creation. This allows the residents to explore different challenges that would be out of reach with other grants. Throughout the term of The Hub there's a sense that the residencies have become increasingly experimental in approach, moving further away from academic research norms and embracing of the arts and lived experience.

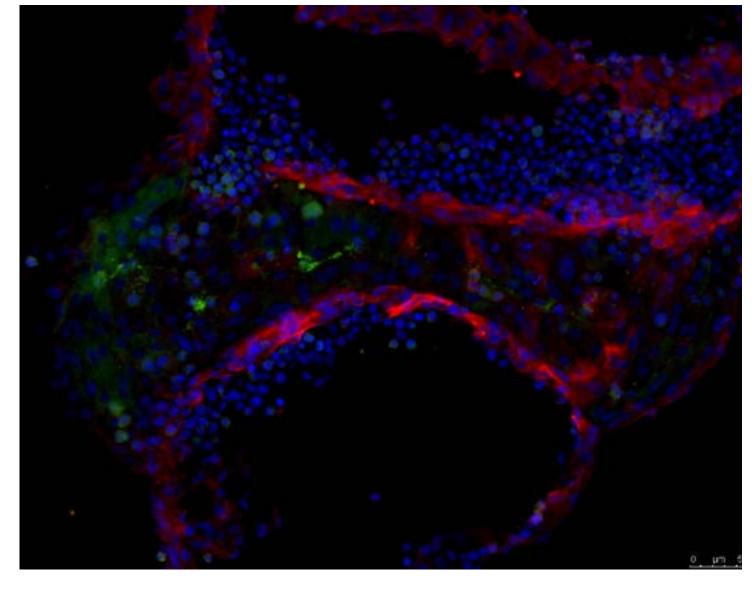
Whilst The Hub may be most remembered for the more creative outputs, a lot of its value still lies in impactful academic publications. Whilst some people hold a perception that transdisciplinary approaches feel less 'robust' than conventional approaches these papers

demonstrate the opposite is often the case. Hubbub produced one such paper on Workfare that was published in the BMJ and benefitted from the direct inclusion of people with lived experience of homelessness and drew inspiration from artworks and other events. This was an influential paper at the time as it was strongly critical of government policy and, as the author notes, couldn't have happened outside The Hub:

"I was able to publish my research in the BMJ, because I had the time, space and encouragement to work to a very high standard. I also had the chance to work with many other colleagues - workshops, exhibition, claimants day out, poetry, art, drawing in the public to raise awareness of the issues, lots of events where there was discussion, debate and public input into questions like 'work for your benefits is that fair?'. I was part of a collaboration with another member of Hubbub where we spent many months working with men living in a homeless hostel, recording their experiences, involving them in writing a paper, which was then presented with the men at a royal Geographical Society conference."

Hubbub

There were also more artistic and even less conventional approaches to knowledge creation. Created Out of Mind experimented with 'growing a brain' from skin cells, see an image of Philip Ball's "mini-brain" below. The types of 'knowledge' this produces isn't necessarily 'scientific fact', but rather acts as a provocation to understand and disentangle sensitive ethical and philosophical issues around consciousness and the brain.



↑ PHILIP BALL'S MINI-BRAIN. The different colours show different types of cell. Layers of neurons are here shown in red. Image: Chris Lovejoy and Selina Wray/UCL







## **3.4 Conclusion**

Through The Hub, Wellcome has created a space where genuinely creative work happens. The inclusion of artists and people with lived experiences, together with the freedom to create their own questions, mean the residencies run projects that are different to conventional grants. Whilst the residents come up with the ideas and conduct the research themselves; the grant, the space, the culture and Wellcome's expertise and prestige all combine to provide the environment and support for them to do so. Wellcome itself is also a reflection of the broader research environment - so the ideal place for The Hub to exert influence and create change. This model can be judged by the variety of work it supports and the range of benefits it provides to different stakeholders. Work from The Hub has directly impacted clinical practice, input into policy reviews, influenced public perception on health, modelled equitable and innovative research practice, developed residents careers and been a spur for new and exciting work to follow. It's clear that The Hub is a versatile set-up that enables different groups with different goals to create new knowledge.

The differences between the way of working for the three residencies so far has been important as it has allowed each to provide more novel insights into specific organisational and collaboration challenges. However, it can be a burden for the residencies themselves to be both researchers and meta-researchers. If Wellcome were to take a more active role in the research-on-research aspect - for example by providing a project ethnographer or providing a clearer framework for capturing learning - then it could free up the residents' time to focus more on their work. It would also allow Wellcome to build up a more systematic understanding of best practice across residencies, this in turn could be used to help advise the residents and the broader research community.



# Chapter 4: Next Steps





In this section we pose a number of questions that have emerged from this evaluation for Wellcome, residents and partners to consider next steps and the future of The Hub. In particular we focus upon how to further improve The Hub experience, to integrate it within the rest of Wellcome, and increase its wider impact.

" I think there's more meaning for a funder or an organisation with a significant reputation to say this is important. It is important that scientists and artists talk regularly to the public and that all of those three constituencies have an important role to play in the research and are equal players in it. I think the times and the atmosphere within the academic world is shifting, maybe partly because of The Hub, partly other broader trends, but there is certainly an appetite for it. It felt like opportunities to do public engaged work were sort of spin offs or add on bonuses rather than... I'd never seen an opportunity previously to make some kind of a central plank of an application."

**Created Out of Mind** 



## 4.1 How might we improve The Hub experience for residents and applicants?

### How can Wellcome develop a thorough application process that doesn't exclude people from non-academic backgrounds?

The application process is highly competitive and very demanding on applicants. However, the way it is designed and the amount of work it creates can be considered exclusionary to some groups - especially those from nonacademic backgrounds who are not used to this type of application or the language used. The Wellcome Hub team are already considered very supportive throughout the process, but what else could be done to maintain quality of application whilst also ensuring that it is accessible to a broader audience?

## and focus?

Hub residents spend a lot of time during the residency developing the questions they want to address, which makes it hard to plan ahead to recruit the right team of collaborators for the research. This search aspect is integral to the way residencies work - and one of the key differentiators from traditional grants - but is currently causing logistical issues and stress for the residents.

### How can residents balance the requirement to be agile and responsive, with longer-term planning

### How to develop and recognise transdisciplinarycollaboration as a skill that is required to get the most from all expertise in the room?

Due to the 2 year time limit it's important for residencies to become highly functioning early on, but running a transdisciplinary team causes new management challenges that the PI may not be used to. The most visible implication of this is tension and stress among some of the team, less obviously it can also lead to collaboration silos meaning the full potential in the team's diversity is not realised. Support in this regard can start early on during the application, so by the time the residency begins the team is able to work effectively together.









### 4.2 How might we integrate The Hub with the rest of Wellcome?

#### How can The Hub and the residents be made more accessible to others in Wellcome?

Currently The Hub doesn't have a high profile across Wellcome, and many of the people in the research teams do not know why, when or how they can get most value from the residents. Whilst residents are keen to inspire and support teams within Wellcome, it's less of a priority than focusing on completing their own research. To fully realise the potential of the residencies then people at Wellcome need to take the lead in strengthening those relationships. Establishing clearer benefits of speaking with the residents and a straightforward way to do so could help Wellcome teams get more benefit from The Hub.

#### How can residents get more value from the expertise around Wellcome?

The residents currently get good support from many of the functional teams within Wellcome - such as Comms and legal - but often find relationships with the academic teams and the Collection harder. This is not necessarily due to lack of interest or enthusiasm from either side, but a reflection of the competing workloads they both feel. By embedding their collaboration earlier in the process - for example including people from the Collection in the design of projects - could be one way to make the relationships more fruitful.

### What does Wellcome want to learn from the residents? How can it be clearer on those expectations?

As the call for applicants is very broad, and currently not designed to fit in with Wellcome's own research strategies, there is uncertainty about what Wellcome want from the residents. In particular, how much they should be documenting their work for research-on-research versus doing the work? In this aspect, they could benefit from having an ethnographic role to document their experience so they're freed up to do the research. It is worth noting that, in future, Hub projects will be required to focus on areas that complement Wellcome's own research strategy - this could improve collaboration with Wellcome teams by ensuring there is a mutual benefit for both sides, but reduces the scope for different organisations that can apply.





## 4.3 How might we increase the wider impact of The Hub?

#### How to realise the value in the unsuccessful applications?

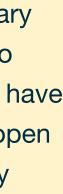
A lot of good work goes into the applications developing teams and thinking through how to approach health research, however for the unsuccessful applicants it is hard to find alternative funding to pursue the ideas. This is disheartening for applicants and a waste of good thinking! There could be opportunity in thinking of ways Wellcome or The Hub could progress these ideas outside of the current 2-year residency format.

#### How can residencies ensure they have a strong legacy?

A lot of value from the residencies only materialises after their time in The Hub. To make the most of this requires planning from the outset about what will happen to the team and how their work will inspire future projects. Creating a longer-term impact plan could ensure the residencies continue to have a strong legacy in the future and give the residents themselves develop the skills and networks to develop their careers.

#### How can the lessons learnt from across the residents be used to inspire best practice elsewhere?

As residencies come and go, The Hub is building up expertise on best (and worst) practice for transdisciplinary collaboration. Some of these learnings will be specific to a team in Wellcome, but some of them are also likely to have a broader application. There could be opportunities to open dialogue with other institutions housing transdisciplinary teams to share experiences and develop thoughts on best practice.







### Many thanks to everyone who contributed their time answering the survey and the interviews for making this evaluation possible.

For more information about this evaluation or The Hub please contact thehub@wellcomecollection.org







weareliminal.co

With thanks to All of the many contributors to this report, the research and the activities of The Hub.

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