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COLLECTIVE INTELLIGENCE IN PATIENT ORGANISATIONS

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EXECUTIVE SUMMARY

Patient organisations as knowledge brokers

This report looks at the often unsung but increasingly important work of patient organisations as knowledge brokers. Patient organisations have played a significant role in networks of health and social care for almost a century. Much of this work has been highly visible; they act as public voices for patients, fundraise, research, campaign, educate, advocate, and provide support services. But we argue that their participation in knowledge work is critical and over coming decades will become one of the most important ways they will advance the interests of patients. As collectives with varied members and activities patient organisations are uniquely capable of building relationships across sectors and cultures, easing the flow of information throughout the network, enhancing its capacity to gather and distribute information and to produce new insights. This can enhance individual participants' knowledge and effectiveness and the collective intelligence of the entire healthcare system.

A changing frame for collaboration

As the store of medical knowledge grows exponentially, methods of data collection and analysis expand, long-term conditions and comorbidities increase and advances in molecular diagnostics identify more rare diseases and stratify common ones, the complexity of decisions and amount of information involved in healthcare is increasing.

Many modern healthcare systems, including the NHS, aim for a person-centred strategy that empowers people in their healthcare. But transferring responsibilities to individual patients without providing support and negotiating transfer of rights and power, risks exacerbating extant resource and health divides.

Patient organisations are in an excellent position to develop their position as information loci and intervene in this effort to distribute the burden and benefit of collecting and distributing, translating, assembling and analysing these information resources.

This is already happening in some spaces. Patient organisations are already driving their own research programmes, collecting and circulating knowledge and data coming directly from patients, and inverting the traditional top down flow of clinical knowledge. They are using digital tools, new governance structures and ambitious partnerships to more effectively engage, educate and empower patients in the project of improving, even saving their lives.

- Our case studies look at My Stroke Guide, a new tool supporting stroke survivors in developing support networks, exchanging information and setting self-management goals; the AKU Society's ambitious research programme driven by innovative partnerships; the intensive support and relationship development of Eczema Outreach Scotland; and the flow of empathy and expertise through a Lupus UK peer-support group.

New tools for collective intelligence

Currently efforts by many patient organisations are hampered by a lack of suitable tools and platforms. Tools that currently exist to aid the collection and exchange of different sources of clinical and experiential information are often laborious to use, severely limited or are proprietary systems that require patients to surrender ownership of their information.

Participatory tools in other fields of science, democracy or software development can serve as inspiration for patient organisations seeking to more effectively engage their increasingly digitally literate members in decision-making. Because such tools scale effectively, they can support groups at multiple levels. The opportunity arises not to federalise, but to connect directly with the energy and expertise of patients.

There are three conclusions that we can draw from this analysis :

1. More appropriate technology

There is a clear need for investment in platforms for collective intelligence in health which leverage the potential of patient organisations. Most e-health initiatives are concentrating on digital tools for individuals and are neglecting innovative solutions to assemble, construct and distribute clinical knowledge among collectives.

2. Learning from leading organisations

Small patient organisations - particularly but not exclusively in the rare disease sector - offer examples of extraordinary innovation and ambition in research programmes that connect and empower patients. They draw on crowdfunding, private platforms, international partnerships with public and private organisations. Larger patient organisations have exciting opportunities to develop on examples of platforms that support knowledge exchange and so build stronger relationships with and between their supporters. By collaborating and sharing lessons and tools, this work could advance faster.

3. New frameworks

There are many challenges involved in producing legal, ethical and scientific frameworks that could allow the integration of all the relevant forms of knowledge and the involvement of varied stakeholder communities. While healthcare is an exceptionally complex field in which to negotiate such matters, solutions developed there could form the groundwork for a rich ecosystem of powerful tools and empowered, expert users.

INTRODUCTION

Patient organisations are already deeply involved in various aspects of healthcare, from providing information to delivering services. Organisations such as Age UK, Stroke Association or Mind deliver services commissioned by the NHS, many others support, inform and connect patients, operating in the spaces between state services. As public health systems come under increasing pressure from rising demand, we expect patient organisations to play an increasingly crucial role. At Nesta we believe that technologies that support collective action will be instrumental for charities and patient groups attempting to address the growing demand amongst people with health problems to understand and manage their own care and participate in the improvement of clinical knowledge.

Patient groups are at the forefront of the development of what is being called **collective intelligence**: the ability to mobilise a networked public on digital platforms to address complex social issues. As organisations which have traditionally been involved in the distribution and production of knowledge among their members, they are in the optimal position to lead the way in extending the integration between citizens and public services. However, unlike many commonly cited examples of technologically supported collective intelligence, such as open source software and Wikipedia, those who engage with patient organisations are not self-selected on the basis of interest and pre-existing skill. They are motivated by health problems of their own or those they care for, they navigate biomedical, bureaucratic, political and social systems to achieve support, understanding and treatment, with the stakes as high as life or death. They require technologies that can support the production, assemblage and distribution of diverse forms of knowledge, the scientific alongside the clinical with the experiential.

This document is part of a research programme on collective intelligence of which patient organisations are an excellent example. The aim of this paper is to provide a preliminary picture of the current situation: the activities, challenges and tools that patient groups are grappling with as knowledge brokers. The term patient organisations covers an exceptionally diverse range of organisations which share a strong engagement with knowledge, usually including research. By examining the nature of the knowledge work they are performing and the digital environments they have at their disposal we are laying the ground for a call to action.

The extraordinary developments we are witnessing in e-health applications and services are primarily centred on individual patients and their carers. This approach, while empowering to some, may disempower those with less experience, skill and confidence in such tools, or who are strained by the effects of ill-health or caring responsibilities. We believe that digital environments aimed at sustaining the collective intelligence of groups of patients would have a significant impact on health services more generally, by more effectively distributing the burdens and benefits of knowledge work. As patients, carers and health professionals face growing stores of information and data, the need for effective platforms to organise, assemble, visualise and exchange knowledge is crucial. The work of analysing and constructing meanings can be done collectively, easing the burden on individual patients. There are some interesting attempts in this direction but there is certainly space for many more and the challenges involved in developing platforms of this type are huge. They raise multiple issues of combining lay and scientific knowledge, of organising data and sources of information, of governance of the system.

THE CHALLENGE AREA

Knowledge is becoming one of the most critical assets of patients seeking to ensure access to treatment, diagnosis, support and satisfactory life conditions.

“Without the Lowe Syndrome Association, I firmly believe that Jonathan would not still be with us as we gained crucial knowledge about his renal function at a medical conference they hosted in 1998 which subsequently saved his life twice.”

Experiences of Rare Diseases: An Insight from Patients and Families

Healthcare has always involved negotiations of biomedical knowledge, bureaucracy, culture and available resources. But these decisions have become more complex as we live longer with more long-term conditions, our stores of biomedical knowledge grow exponentially and molecular diagnostic technologies and data gathering opportunities provide us with swelling reserves of potentially relevant information. Traditionally health-related knowledge has been distributed among researchers, clinicians, and health practitioners. Patients have been perceived to be on the receiving end of the knowledge flow. Recently however, there has been a recognition that patients want and are able to take greater responsibility for their care and we are witnessing a progressive shift towards self-care, expert patient roles and peer support.

The public have increasing access to information sources and opportunities to educate themselves. The NHS has called ‘engaging, empowering and hearing’ patients a key goal.¹ But at the same time the amount of time available for key interactions such as the GP appointment has shrunk. The information patients access independently will vary in quality; though much may be valuable some will be partial, some false, some even deliberately exploitative. Patients’ ability to communicate to clinicians their understanding and opinion of complex information, may be influenced by many factors other than the condition and their knowledge; their working relationship, the patient’s education level or socioeconomic status, etc.

It is difficult for clinicians facing extreme time and resource pressure, even in the most egalitarian practices, to sensitively discuss a patient’s own research, verify sources, place new information in context, and have a considered conversation all within the ten minutes of an average appointment. This time-pressured negotiation is further complicated by the clinician’s competing concerns – which are often invisible to the patient – of balancing budgets, managing referrals, the cost and availability of medicines and the challenge of keeping abreast of new research.

Donald Lindberg, director of the National Library of Medicine famously stated in 1999 “If I read and memorised two medical journal articles every night, by the end of a year I’d be 400 years behind.”² The rate of publication has been rising exponentially since the 1950s and this pace of development is unlikely to slacken. It is impossible for any single clinician with responsibility for hundreds or thousands of patients to maintain cutting edge expertise in every strand of research pertinent to every one of their patients’ varied presentations, mutations and co-morbidities, let alone integrate that with a detailed awareness of those patients’ personal circumstances, responsibilities, health literacy, and attitudes to risk.

For a long time, many patients have done supplemental information work. This can include finding and managing information about their condition, keeping up to date with research into treatments, managing their care and that of loved ones, organising schedules of treatment including requesting, scheduling and keeping multiple appointments, and maintaining relationships with relevant individuals and institutions. This work often goes acknowledged, but when it is left undone their use of the system's resources are less effective: appointments are missed, consultants do not receive relevant information, new findings or treatments are not accessed. Patients do not always have the rights and resources necessary to take on the task of managing their own health. They may be barred from accessing their own records, or research pertinent to their decisions.

Shifting responsibility to patients without offering comprehensive support is likely to exacerbate extant divides. Knowledge work is hard, takes time to learn, and the people facing these new challenges are already strained by the effects of ill-health. We know that people who have more income and education can achieve more accurate diagnoses,⁴ make more use of the healthcare system, and have better health outcomes overall. The problem resists simple solutions such as digitising records. In fact implementing patient portals has shown patterns of use which reflect existing resource disparities, raising the worrying implication that efforts to transfer rights and responsibilities to patients by offering digital services without accompanying education and support could increase disparities.⁵ People who do not have additional social, educational and fiscal resources to bring to the challenge often struggle. They receive less accurate diagnostics, less effective treatment and care, so achieve worse health outcomes.

A vital, yet underexamined aspect of the disparity in healthcare is social capital. Access to a wide social group does not only grant access to material resources, but even more importantly to epistemic ones. **Belonging to a large network through which knowledge is distributed is a huge advantage in improving one's understanding of and access to relevant medical information.** There is extensive research demonstrating the tight causal relation between isolation and morbidity which again can be interpreted not only in emotional and material terms, but also cognitive ones.

“ Even though I have a small group of friends and my sister to whom I can talk about Lupus, in the [peer support] group I can still say more, learn more and do more by talking to other Lupus sufferers. The group is a source of information even when things don't affect me directly. I write them down and then go and research them online on my own. They make me aware of signs I should be wary of, things that may affect me in the future. It will allow me to do something about it sooner.”

Margaret, member of Lupus UK

In the light of this challenge, the role of collectives such as patient organisations is crucial. Sitting between stretched health services and strained individual patients, collectives are increasingly taking on the work of assembling relevant knowledge and giving guidance to patients and researchers alike. The most successful patient organisations have formed institutions which significantly contribute to the process of circulating and integrating knowledge: holding expertise, drawing information from both sides and collectively doing some of the thinking work that is so crucial in the evolution of effective care.

A HISTORY OF PATIENT GROUPS

People with health problems have a long history of coming together and taking advantage of available technologies and governance systems to mobilise their collective energy and intelligence more effectively. The first groups that institutionalised as charities seeking to be the central hub of information for a specific condition or disease area emerged in the closing years of the First World War. These first patient organisations were centred on common conditions – Macmillan Cancer Care in 1911 and Diabetes UK’s predecessor shortly afterwards.

The Diabetic Association

In 1934 author and scientist H.G. Wells and Dr R.D. Lawrence published a letter in *The Times* – the nearest available equivalent to one-to-many peer-to-peer publishing – announcing the launch of a charity “to promote the study, the diffusion of knowledge, and the proper treatment of diabetes in this country.” Both Wells and Lawrence had diabetes and owed their lives to the newly available insulin. In these early years the Diabetic Association funded research, but prioritised the dispersal of information and skills, in particular the democratisation of the new life-saving, life-long treatment regime. Lawrence developed and spread ‘diabetic kitchens’ to teach practical skills related to insulin and lifestyle changes, and forged early networks of self-support groups. After several name changes, it became Diabetes UK in 2000.

The information work of these early groups and those that proliferated after the Second World War was primarily focused on developing the skills of lay patients. The 1980s saw activists from communities ravaged by HIV/AIDS and from disability groups seeking to actively intervene in the public, political and scientific discourse that framed their health problems and informed their identities and treatment options. HIV/AIDS activists intervened in public discourse with dramatic public protests that resisted the obfuscation of stigma. This intervention affected the incentives and activities of the research community. But they also actively reshaped the system through which knowledge was produced and enacted, by redefining the relation of clinical trials and care.

They found ways of presenting themselves as credible within the arena of credentialed expertise. At the same time, these activists succeeded in changing the rules of the game, transforming the very definition of what counts as credibility in scientific research such that their particular assets would prove efficacious. ...[This showed] the danger of understanding the role of laypeople in scientific controversies solely in passive terms.⁶

These groups established themselves not resources to be drawn on by the expert medical community, but active agents of change with their own resources and agendas.

Around the same time the disability studies movement began to raise concerns and criticisms of the medical profession’s power to shape the identity of persons affected by disabilities, through their control of biomedical and public discourse. Disability studies activists asserted the “precedence of individuals’ subjective experience over any objectifying knowledge,

*especially medical knowledge.*⁷ They claimed the right to shape the social representation of their disease. Over time the label 'lay expertise' grew to encompass elements of biomedical expertise, cross disciplinary expertise and relationships, social activism regarding stigma and identity politics, and the authority of the lived experience of a disease.

The spread of internet access brought an explosion of new groups. Peer-to-peer publishing and new discovery tools were especially valuable to groups supporting those with rare and contested conditions who had previously struggled to connect. These groups could draw on both the new digital tools and the models of empowerment and expertise established in preceding decades to pull their problems into the realm of biomedicine where recognition, research and treatment could happen.

In the 1990s Caroline McGraw and Elizabeth Pulsifer-Anderson, both of whom had several children with severe gastroesophageal reflux disease, found one another through the internet and formed an online support group for similarly affected families. Despite their clinicians' denial that the disorder could be passed on, the group exchanged experiences and gathered evidence of inherited GERD. After years of reaching out, they found collaborators at a research hospital. The team's survey of support group members was supported by a series of whole genome sequences. In 2000, a peer-reviewed paper demonstrating the responsible gene was published in the JAMA with the lay support group leaders as co-authors.^{8,9}

There are many examples of small groups focused on specific disease areas developing tools and structures to connect, educate themselves, gather evidence, build networks, and further research. Sharon and Patrick Terry founded PXE International in response to the disorganisation of available information and lack of any ongoing research into the genetic disorder, Pseudoxanthoma Elasticum, that affected their children. Without any prior medical training, they funded and conducted an ambitious research programme. They were so deeply involved in the process of discovery that Sharon Terry is credited on the patent for the ABCC6 mutation which causes the disease. PXE International holds the patent with the intention of keeping it available to research, avoiding the barriers that might be put up by owners such as pharmaceutical companies who are incentivised to publish discoveries themselves. Together with other organisations they have *"created common infrastructure, including templates of documents, agreements, protocols and procedures to allow affordable and efficient replication of these successes"*¹⁰ These include co-operatively owned biobanks for rare disease groups.¹¹

In the UK the NHS provides many services, such as biobanking, that tend to be privately controlled in other countries, most notably the US. This means there is less incentive to self-organise open alternatives. Many charities take up complex and creative partnerships with NHS services. For instance the AKU Society encourages members to have samples collected during operations to give to an NHS-run biobank. Relations with the NHS are affected by the NHS's attempts to engage with patient knowledge in other ways. There is a longstanding commitment to Patient Participation Groups, made up of volunteer patients and staff who work together to improve their local practice and its services. Digital tools are being developed to facilitate other kinds of engagement with state systems. NHS Citizen is a new service intended to include patient voices in major strategic decisions within NHS England. Another initiative, Dementia Citizens, supported by the Department of Health, Nesta, the Wellcome Trust, Alzheimer's Society, Alzheimer's Research UK and others, connects patients and carers directly to researchers.

The emergence of collective intelligence

As groups grow and engage with more and more complex challenges, they need more complex governance systems, and it becomes more difficult to incorporate the interests and intelligence of members into the decision-making process. For a long time there were no tools capable of managing the energy and intelligence of collectives at a large scale that did not demand elite technical skills. This affected small, tightly networked groups attempting to scale, and large, established groups attempting to distribute power and intelligence amongst their members. While the open source movement has produced extraordinary examples of networked publics distributing the burden and benefit of hugely complex cognitive work, such as Linux in 1991, engaging with these tools requires deep understanding of coding environments and access to systems.

As late as 2012, adults living with chronic disease were significantly less likely than healthy adults to have access to the internet.¹² While access has improved, and our ethnography of Lupus patients repeatedly demonstrated that patients were enthusiastic users of social media tools, the patient movement suffers in comparison to groups self-selected for interest and skill in technical development. Several of the larger, older charities we interviewed explicitly recognised that they had inherited a culture of top-down delivery which had weakened ties with their lay membership. Attempts to change this culture were slowed and undermined by poor tools. Smaller charities were more likely to complain of the effort of keeping track of their information resources and intelligence and the limiting factors of their manual approach to management.

New tools for both individual health management and large-scale data management and mining are being developed that may enable patient organisations to leverage the collective intelligence that has always been at their core. However, as we will see in a further section, these are still few and limited in their scope. There is a huge potential for developing systems that would allow collectives to assemble, organise and visualise information in a much more systematic yet accessible way supporting more effective learning.

There are numerous challenges involved in assembling these new knowledge environments, some of which patient organisations are already facing. Information of different kinds, can be difficult to interface, and can have different status. For instance **credentialed information**, such as the findings of clinical drug trials, has been through multiple levels of review to confirm its facticity; a standardised procedure in a credentialed lab performed by qualified people, submitted to peer review. **Experiential information**, such as reports of experience of pain or exhaustion, or skill at negotiating situations and relationships, may be more direct, but is much harder to verify, and is often perceived as being of lower status within the healthcare system.

Individual patients have few options for improving the status of the information they have, or for shifting its form. They must navigate appointments with credentialed professional gatekeepers such as GPs, a negotiation which is generally undertaken under time pressure and is often more successful for people with higher socioeconomic status. **Patient organisations have the strength to haul information from the experiential domain into the credentialed** through surveying or otherwise researching their members' experiences.

Patient organisations can draw on deep relationships with patients, healthcare professionals and other stakeholders to translate information from one domain to another. The most common example is the translation of biomedical information such as the data of test results, or the technical detail of peer-reviewed papers into forms usable by people who may have little relevant biomedical knowledge, and who may be experiencing the shock and grief of a new diagnosis. Patient groups have found spaces within these tools and unstable relationships, acting as hubs and brokers of information, even of tissue and samples, providing moderated and guided discussion spaces.

PATIENT ORGANISATIONS: DEFINITIONS

By many accounts patient organisations are booming: they direct significant sections of public research spend, they are driving discovery, campaigning for policy change, and increasingly stepping in to support where budget constraints afflict state healthcare. Yet the field remains largely unmapped. The European Patient Organisations in Knowledge Society concluded that *“there are no robust statistical data on this phenomenon”*.¹³

Many of the features that make these organisations so productive are the same as those which make them unmappable. Patient organisations often work in the gaps that open up between individuals and institutions and alter their form to fit changing needs. The intention for many initiatives or entire organisations is to render themselves irrelevant; to *“work until we turn the lights off and go home.”*¹⁴ Groups may grow, shrink or close down according to the changing capacities of core members, they may engage in partnerships, consolidate or split. Communicating these changes will often be a low priority for resource-strained groups.

“*There is constant churn especially among the smallest patient groups. One or two people set up a charity and run it on a voluntary basis for as long as they can. But they might have to close, and other people start new ones – it happens all the time. Many of the smaller ones will never be registered as charities.*”

Amy Hunter, Senior Research Manager, Genetic Alliance UK

Definitions of exactly what a ‘patient organisation’ is are challenging and risk being exclusionary. Those at most risk of exclusion – those with novel forms, networks which overlap and intersect with private and state actors, organisations closely affiliated with or even nested within one another – are exactly the places where instantiations of collective intelligence are likely to be found.

The International Association of Patient Organisations (IAPO) provides a useful definition as *“Patient driven organisations which are non-profit and non-governmental, legally recognised by the state, committed to patient-centred care.”* But the definition is essentially a judgement call by staff. To qualify as ‘patient driven’ the majority of voting members or governing body must be patients or patient representatives, or the organisation can explain their claim to the status in a written submission.¹⁵ Further, they permit associate membership from groups that are not patient driven, but commit to the ‘principle of patient-centred healthcare.’¹⁶ IAPO staff explain that terms must be flexible to accommodate the very different institutions and cultures they encounter working in different regions across the world.

Many ‘patient’ organisations, particularly those that work in a disease area which has no cure or for which diagnosis is challenging resist the centring of the patient, and the label patient organisation. Alzheimer’s Society staff explained their resistance is multifaceted: much of their work is with carers, many people with dementia are undiagnosed or improperly diagnosed, stigma attached to the diagnosis complicates their communications with those affected, and they see change in the community and public discourse as being as important as direct

support to the individual. We recognise these problems but use the term ‘patient’ in this report because throughout interviews with organisation staff, and the ethnography of peer-support groups we found that the term was broadly used and all alternatives were similarly contested. ‘Patient’ should be understood as those with health problems.

“ *Our statistics suggest that around 50 per cent of people with dementia have a diagnosis, and if they have one it may be inaccurate.*”

Staff member, Alzheimer’s Society

Patient organisations often count professional clinicians amongst their members and staff and work alongside or even within state health care systems: the AKU Society has two staff members funded by the NHS to support the AKU centre of expertise in the Royal Liverpool hospital, The Stroke Association is paid by Clinical Commissioning Groups (CCGs) to deliver Life After Stroke services to 69,000 people across England and Wales.

“ *There are arguments about basic definitions. Patient can be a very isolating term. Many people don’t want to be labelled, and their condition may carry stigma. Some international members prefer ‘health consumer’. We try to make it very inclusive – everyone will visit a doctor at some point, or have a health issue to deal with.*”

Megan MacGarry, Senior Membership Officer, IAPO

A key finding was that those groups which were members of robust umbrella groups such as Genetic Alliance UK and the Association of Medical Research Charities were much easier to access and analyse. We must echo the call put forth in Branfield and Beresford’s report *Making User Involvement Work: Supporting Service User Networking And Knowledge* for a ‘national register’ as a key first step in improving the visibility, accessibility and status of such groups. Such a register might prove a challenge for all the reasons of mapping and definitions described above, but would prove hugely valuable to the NHS for a relatively low cost.

For our purposes, the IAPO’s broad definition has sufficed, though we have been open to organisations which are partnerships at their core. Those groups which engaged most actively in collective intelligence activities tend to be porous and interdependent. Digital tools that take on some of the practical burden of relationship management enable networks that are more fluid.

Categories

The patient organisations that fall under our definition are a varied, nebulous group, but clusters of features can be categorised. It is broadly true that large established organisations can leverage more resources and are both supported and constrained by their established institutional structure. Their long histories of operating under resource constraints and the sector's traditional aversion to risk can exacerbate this inflexibility. Smaller organisations are more fluid; nimble yet vulnerable. As has been explored in more depth by Branfield and Beresford's work with service user organisations, fluidity is not as valuable an asset to such groups as comparisons with the private sector might suggest. Small health charities operate in a landscape defined by interactions with larger institutions. They can collapse under the burden of bureaucracy necessary for working with the NHS, social care services, local councils, schools and other institutions, of accessing grants and proving adherence to process and deliverables, interpreting legal and policy documents, working with children or vulnerable adults.

The big charity/small charity characterisation is strengthened by considering the influence of the characteristics of each group's condition of interest. While big charities started small, small charities that were established recently are less likely to grow according to a similar pattern because the health problems they centre on are rarer. The charities that serve populations affected by stroke, diabetes, Alzheimer's, heart disease, broad groups of cancer, have hundreds of thousands, even millions of patients to support and to draw support from. Charities which serve rare diseases – defined in the EU as affecting fewer than five in 10,000 people, will not see that population grow. In unusual circumstances charities supporting rare conditions can see huge injections of funds; for example the US's ALS society received worldwide recognition and over \$100 million funding from the Ice Bucket Challenge despite the condition affecting only two in 100,000 people. But the condition remains rare and affected population small. Whilst there are exceptions, and 'rare' is itself a broad category, ranging from tens of thousands to dozens, small charities are not attempting to become big ones.

While instantiations exist at all points along the spectrum, we have found value in the broad terms 'big charity' for those groups which have the resources to take up longer-term strategies and hire according to their needs, to differentiate from 'small charity', who tend to be limited to funding shorter-term projects are reliant on the skills and resources available to volunteers and core members who are motivated by personal experience of the condition of interest. Once again the differentiation is not absolute. 'Small charities' often have some third sector professional staff, but the majority of their core staff are motivated by a connection with their condition of interest. 'Big charities' often have a volunteer network assisting in the provision of some services, but the majority of staff are not affected by the condition of interest.

Big charity's capacity to enact longer-term funding and strategies contributes to stronger relationships with key external stakeholders, who can in turn collaborate on advancing longer-term funding and strategies. They can invest in expertise and interrogate or even contribute to policy on the national and international stage. Small charities can form tight bonds with their smaller network of members, and remain highly aware of their needs. But limited capacity can restrict them to short-term projects and intermittent funding.

Large, established groups and small, vulnerable groups both tend to want to achieve the positive features more easily available to the other. Big charities want to foster tight bonds with members, and provide them with community support. Small charities want the advantages of relationships with key stakeholders such as policymakers and pharmaceutical companies, and to enact change in national and international policy. In order to achieve this, small charities, when possible, join umbrella organisations that co-ordinate resources and messaging, and invest in building expertise relevant to policy interventions. Big charities develop or fund local chapters.

BIG CHARITY	SMALL CHARITY
Hires professionals according to need	Draw on volunteers/motivated members
Long-term systems and strategies	Fluid, responsive
Institutionalised, professionalised	Centred on key individuals, 'labour of love'
Relationships with external stakeholders	Strong relationships with patients
Common diseases/broad disease areas	Rare diseases/specific subtypes of disease

Big charity

Where a smaller charity can invite contributions and feedback through email and phone calls and manage many engagements through personal relationships, a charity which supports tens of thousands of people must employ layers of systems and management. These systems, institutional relationships and investments represent significant fiscal investment and stores of crystallised cultural knowledge. Attempts to harness members' intelligence and energy without re-evaluating the power structure within which such interactions exist risk being tokenistic. Many of those we interviewed in big charities were explicitly aware of this concern, and worked to effect deep-seated cultural change. But such efforts are continually weighed against the need to use members' money effectively in the present to do research, offer improved services and treatments and lives for those in need right now. Big charities are understandably cautious, and interviewees reported a pressure to see examples of success before investing their donated funds. Still, there are many examples of enthusiasm to effect long-term change, to take on ambitious network-building projects, and to seize opportunities

for change in the short term. Almost all of the large charities we spoke to had taken up a James Lind Alliance Priority Setting Partnership to realign their research priorities according to a new consensus of patient and expert stakeholder interests. Most had panels of lay readers inputting on research funding decisions, patient advisory boards, regular surveys and co-production workshops for new services.

The empowerment and involvement of members is a key factor in authority claimed by these large groups, long entangled in state services, to represent those affected by a disease area. With ever more digital tools for sufferers to connect, mobilise and publicise their views outside of established charities, these claims to authority are not impenetrable. As digital users' expectations of representation develop pressure to improve participation grows.

Small charity

Small charities are characterised by close relationships and shaped by the pre-existing cultural, social, educational, fiscal capital of members. Many are 'labours of love' centred around a core team or even an individual motivated by experience with the condition of interest. Many of the participants thus motivated are affected directly by the effects of ill-health or by the responsibility of caring for a someone affected. Small groups whose affected members manage heavy burdens of ill-health or care may not survive a change in circumstances of a core members. These close relationships and strong personal motivations can be extremely productive. Experiments in enhancing the group's collective intelligence are hugely attractive given the lack of other resources. Drawing on the knowledge and energy of members is a necessity, and the bodies and experiences of patient are often a key, scarce source of data necessary for progress towards treatments.

PATIENT ORGANISATIONS ACTIVITIES

While patient organisations vary hugely in scale and resources their core offerings to members are strikingly similar. They offer assistance and empathy to members for their immediate concerns and work to improve the treatment and care options for the future, often including the hope of finding a cure. Needs will vary according to the characteristics of the condition, including socially constructed characteristics such as stigma and perception.

The balance of work varies. A group's focus is shaped by the characteristics of its condition of interest and the characteristics of available treatment and care. For AKU, a condition which is painful and debilitating in adulthood, whose cause is well characterised and for which there is a promising treatment, it makes sense to invest in speeding progress to a cure. For severe eczema, which is painful in childhood but usually self-limiting, has poorly understood immunological causes and triggers that vary between individuals, it makes sense to invest in peer support for families and advice for alleviating symptoms. In the case of dementia¹⁷ biomedical advances have revealed that it is actually a collection of conditions, none of which have a cure on the near horizon. Experience of the condition is entangled with other a social and biomedical functions of ageing, and the heavy care burden it imparts on families. As the condition is so common, there is space for a number of different approaches, although it is hugely underfunded compared to other major conditions.¹⁸ Thus it makes sense for Alzheimer's Society to focus resources on public education and community development and effective care alongside research into cures, while Alzheimer's Research UK is solely dedicated to biomedical research.

Core offerings relating to collective intelligence

- Biomedical research into new treatments, care options and cures.
- Policy change and social activism.
- Experience exchange and relationship development.
- Producing and exchanging accessible information.
- 'My story.'

These offerings are often interconnected. Initiatives are often expected to serve a dual purpose - meetings that involve information sessions will naturally have a social element in which members can build relationships and seek advice from one another. A dedicated time for discussion of mental health concerns related to chronic pain on a Patients Like Me forum will encourage patients to sign up to the platform and input clinical information, quantifying more of their experience. A survey that collects information about symptoms exposes the surveyed population to medical terms and definitions that will help them frame their experiences when explaining their problem to clinicians. Public education that improves perception of a condition often doubles as fundraising. Exchange of disease narratives strengthens relationships and facilitates the spread of expertise.

The points at which these offerings overlap are often the points where patient organisations look the most like collectives – with energy, expertise, empathy and intelligence exchanged rather than provided from a central source, but the tools often do not exist to successfully support such work. Many of those we interviewed expressed frustration at the wealth of information they glimpsed being exchanged in online support forums, particularly around side-effects and drug interactions, failures in state services, which they did not have the capacity – technological tools, governance and ethics procedures, or staffing levels – to access. Some groups had turned to collaboration with Patients Like Me, a private platform that has developed tools and systems to datafy patients' reports of symptoms, but does not mine its forums. This tool was productive for some, and proves the value and need of similar tools but did not solve the core problem and raised issues of access and ownership of information.

Furthering biomedical research

Patient organisations use their size and resources to influence biomedical research ecosystem to suit their members in many ways – their limited resources often inspire creative and tactical deployment of funds and information. They engage with pre-existing incentives within the private sector and academia.

The market provides its own incentives for many aspects of clinical research – most often those that will produce saleable treatments to profitable populations. The state funds further research, particularly focused on those with an impact on wide population health and care burdens. Patient organisations engage actively with the pre-existing incentives and funding and seek to reshape them. Several patient organisations allied to campaign for the Orphan Drug Act of 1983 in the US, which reshaped commercial incentives for the development of treatments for rare diseases.¹⁹ EURORDIS, an alliance of European patient organisations supporting those with rare diseases, campaigned for similar legislation in the EU in 2000.²⁰

Patient organisations provide incentives that are meaningful to researchers, such as arranging conferences and special issues of journals that provide opportunities to publish, promote and connect their work and gather credibility. They may attempt to make their condition of interest more attractive to researchers by rendering health information more accessible. Simply making patients who are interested in participating in research available to contact quickly and easily can be a significant incentive to researchers with limited schedules and budgets.

Charities have developed tools to manage such registries such as Reg4All, developed by Genetic Alliance US. Or they may use private platforms such as Patients Like Me. If genetic data or tissue samples are available the incentive grows. The NHS provides a state biobank which is open to privately and publically funded research, but charities may support sample collection. The AKU Society works with the NHS in their AKU Centre for Expertise to arrange that patients who are having joint replacement surgery have bone samples taken which are made available to researchers. In the US, patient organisations have been motivated to set up their own co-operatively owned biobanks because privately held ones were not made accessible by their owners to competitors.²¹

Charities fund significant proportion of research in the UK – consistently contributing over a third of publicly funding research.²² Charities spent £1.3 billion funding medical research in 2013, and spent more than £1 billion a year in the six previous years, consistently contributing over a third of publicly funded research.²³ They are also tactical when they directly fund

research. Interviewees at several larger charities explained that this could mean investing in early-stage research, with the intention of providing evidence that makes an avenue of research attractive to commercial investors. They noted that while the tactic was productive, it sometimes caused messaging problems when trying to explain how donations to research impacted treatments – it was hard to communicate the link between a treatment delivered by a commercial company, and the early-stage research funded a decade earlier.

There are numerous examples of parents racing against time to find treatments and cures for their children. Some, like Jannine De Mars Cody, who gave her 18q- daughter human growth hormone and reversed the condition's expected loss of IQ and stunted growth, succeed.^{24, 25} The prevalence of such close personal connections translates into high motivation and activity. Sixty per cent of Genetic Alliance US's survey respondents had, in the two years preceding the survey, provided financial support to a researcher. They were also likely to be actively involved in the process of research: 91 per cent had assisted in participant recruitment, 75 per cent collected data, and 56 per cent assisted with study design.²⁶ They also returned this information to their members, and to the expert community: 89 per cent shared results through their website or newsletter, and 60 per cent supported a scientific conference.

Challenges and opportunities:

- Negotiating relationships with the research community is hard; differing expectations and incentives can lead to disappointment. Twelve per cent of surveyed members of Genetic Alliance reported regretting providing funding assistance to a research project, most often due to lack of progress and communication breakdown. Groups who had found success told us that they attributed much of it to luck in finding well-suited partners. Tools and systems that support the development of such relationships are vital.
- By taking on the challenge of connecting researchers with patients, maintaining registries and brokering connections, patient organisations must take on complex legal and moral negotiations of ongoing data protection, informedness and consent. Tools such as Reg4All and EnCoRe at the Oxford Biobank represent attempts at solutions, but more work and support in accessing such tools are needed.²⁷
- The bureaucratic and biomedical expertise required to participate actively in research networks is often enormous, and small charities reliant on a few core members struggle to invest the resources in attaining it and retaining it over time. Umbrella groups such as AMRC and Genetic Alliance UK provide support, and AKU Society's CEO Nick Sireau recently launched Findacure, a charity developing support tools and networks tailored specifically to rare disease patient organisations participating in biomedical research.

Policy activism

Convincing national governments and international policymaking bodies to change policy, law and spending involves engaging with a complex system of politics and ideology, national and industry interests, influence and evidence. Relationships and expertise are key, and the financial and time cost of involvement is high. Methods of distributing the expertise and effort required are vital.

INCADDS The Irish National Council of ADHD Support Groups and Affiliated Organizations was formed in July 1999 as an umbrella organisation emerging out of a network of local ADHD support groups which had been established across Ireland during the 1980s and 90s.

These self-help groups were established by parents of children with ADHD to provide mutual support and advice. Experiential knowledge was therefore a key driver in establishing INCADDS, although a number of professionals (in particular a psychologist from the US) also played a key role in establishing the group.

The group was formed out of a recognition that a national voice on ADHD was required if they were going to effectively influence government and policymakers. INCADDS' two key aims revolve around (i) awareness raising and (ii) mutual support. Central to awareness raising activities has been the construction of ADHD as a little known about, and under-diagnosed, condition, in which Ireland 'lags behind' other countries in the world (particularly the US).

EPOKS European Patient Organisations Knowledge Society

It is not unusual for larger groups that are recognised as authoritative voices for their condition of interest to be asked to contribute to policy decisions. Smaller groups can struggle to intervene in policy. Relationship building and events that require physical attendance, pose a particular challenge given that many members are affected by ill-health or caring responsibilities for very ill relatives. Groups which are overly reliant on individuals and 'labours of love' are particularly vulnerable. To counter this, small groups can join umbrella groups. Genetic Alliance UK and National Mind and international groups such as European Parkinson's Disease Association draw on the concerns and interests of their member groups, which are all patient organisations, and negotiate the expert work of building national and international relationships, navigating bureaucratic and transforming information into deployable forms.

Collecting information and transforming it into forms that are effective in policymaking spheres often takes specialist skills. Larger groups can hire skilled staff and invest in long-term strategies. Some smaller groups employ limited resources creatively; the AKU society employed an accountant to estimate the cost of a single AKU patient to the NHS, and was able to demonstrate a clear cost-benefit analysis that supported their request for funds for a specialist centre. Rare Disease UK interwove patient narratives and quotes with statistics in its report *Experiences of Rare Diseases: An Insight from Patients and Families*. These narratives brought failures in long-term care to light and strengthened a case which could have suffered because, being focused on rare diseases, the pool of responses at 570 was relatively small. Groups undertake and commission research that is valid in policymaking circles, much as they do in biomedical realms facing many similar challenges. Surveys are a popular method of turning individual experiential accounts into evidence of wider need. Groups also draw on their long-standing relationships with different members of the organisation's network; patients, clinicians and researchers, and other stakeholders.

Challenges and opportunities:

- As with biomedical research, the level of expertise and investment required to participate actively and effectively in policy making can be enormous. Umbrella groups help those groups within their remit pool resources and achieve common goals. Because many such groups are funded by small groups they can be intensely vulnerable themselves.
- Simple survey tools, forums and social media platforms are not up to the challenge of permitting larger groups of members to contribute to strategic decisions about policy and activism. Examples such as Loomio exist, but they are not widely used, and any uptake is accompanied by the challenge of educating and engaging interested members in the many bureaucratic and biomedical issues impacting on policy activism.

Empathy exchange and relationship development

“On this platform people generally exchange support, not solutions. They don’t want advice or to be told ‘you’re saying this because you have this condition’ because they experience that kind of solutionism and judgement elsewhere; here they want to say ‘I feel this way’ and have others respond that they do too, and that they understand.”

Staff member, Mind.

Health problems can bring with them profound changes in personal circumstances, new experiences and changes in an affected person’s sense of identity. The cognitive distance between a sufferer and their unaffected peers can be stretched to breaking point. The resulting isolation and anxiety can be a significant barrier to patients needing to take an active role in their own care. A common feature of Lupus sufferers’ accounts was that over the course of their long illness they had seen many relationships with friends and family wither as those not affected by the condition could not understand Lupus’ symptoms of fluctuating levels of energy and pain. Friends often perceived a sufferer’s repeatedly cancelling arranged meetings as a personal slight. Several referred to the Lupus peer support groups they attended, some of which had been meeting for several decades, as a family.

People with shared experience can provide empathy and a sense of being understood and recognised without pity. Most of the charities we spoke to reported the value to their members of providing a ‘place to vent’. This was often a simple online forum, or in smaller charities a space on a pre-existing social media platform, most often Facebook. This network building strengthens support networks and secures trusted channels through which information and resources might be effectively distributed. Relationships made across phases of engagement can draw patients forwards through phases. Some charities codify this process of relationship building across levels of experience in befriending and mentoring services. Some schemes, such as one delivered by Connect bringing patients with Aphasia together, are produced and delivered by charities but funded by the NHS,²⁸ which recognises the value of such connections.

“ I felt paralysed with fear; I couldn't move, eat, or go outside. But then I met Bernie... I knew I could trust her because the Stroke Association put us in touch... She's had two brain haemorrhages so when I heard about her health problems and how far she'd come, she gave me the confidence to think, 'If Bernie can do it, I can do it.' ”²⁹

Stroke survivor commenting on befriending service, Stroke News 2014

Several groups noted that certain populations were harder to reach– Eczema Outreach Scotland for instance redesigned some of its support sessions around practical activities to encourage attendance from members, fathers in particular, who reported being uncomfortable talking about personal difficulties in public.

When patient organisations provide members with the opportunity to meet to share empathy and narratives, they build relationships of trust and channels through which information can flow. Individuals may notice patterns in experience or in interests through this informal sharing. Organisations can, given suitable governance and technological systems, collect this information and present it as evidence usable within the research community. While examples such as the discovery of inherited GERD described above are available in smaller groups, tools are lacking for larger groups and much of this information is lost. Genetic Alliance initiative Reg4All is intended to provide tools for patient organisations to run their own surveys providing an output usable by clinicians, and some groups use Patients Like Me, but so far these solutions are partial.

Spaces to communicate in person or online can present problems though. Members of the Lupus UK peer support group said that sometimes they avoided going on online forums, because reading other patients' negative accounts made them feel depressed and hopeless. On National Mind's online forum Elefriends, moderators recognised that excessively negative or aggressive comments could be dangerous to other vulnerable users, so they occasionally had to make difficult decisions regarding the visibility of negative posts from people in distress. National Mind developed a custom platform that included features specific to the intention of providing a supportive space primarily for people experiencing mental health problems. The tool was developed through co-production workshops with users, after experiments with a Facebook group. The development team are committed to an ongoing iterative development, so the platform can evolve with users' continual feedback.

Many patient organisations offer members the chance to physically meet. Whilst these are often workshops with a specific goal, peer support, they may simply be a chance to spend time performing unrelated activities with other people facing the same health problems. The scale and regularity of face to face meetings is influenced by the commonness of condition. Patient organisations for common conditions may be able to provide regular local support groups targeted at different audiences (such as different age cohorts, different BAME groups). Patient organisations which serve rarer conditions may join together with related conditions to attain sufficient numbers for infrequent events.

Challenges and opportunities for development:

- Generic forum tools may not serve patient communities with specific needs. Stroke Association’s My Stroke Guide forum is designed to be usable by people with motor and cognitive disabilities. Mind’s Elefriends forum has an ‘I hear you’ button –a neutral version of Facebook’s ‘Like’ button– so that users could express sympathy and support when they weren’t well enough to type a full response.
- Moderating decisions can be complex and sensitive– users in distress can post. content which might be upsetting or even dangerous to others in vulnerable states. Decisions regarding how to share power and decision-making could be better supported by new tools.
- Forums and other text-based exchanges are not used as effectively as they could be as sources of information about patient experiences, identifying problems in service provision, or patterns in symptoms.

Lay-friendly information

Patient organisations translate complex biomedical, bureaucratic and expert information into formats that are accessible and usable by people when they need it. Patient Organisations can develop and maintain longstanding relationships across different silos of expertise. This means they can translate between different institutional cultures and disciplinary jargons to develop resources that can be tested and honed for effectiveness in specific use cases, and enable different groups to communicate more effectively.

Many of the charities we spoke to tried to engage wide networks in the production of information, but they were limited by resource shortages. In smaller charities those writing a website’s copy or a leaflet were often volunteers who had personal experience of the condition. Larger charities could bring in experts, patients and professional copywriters together in co-production workshops using processes that could be accredited by the Information Standard. Conforming to the information standard demands considerable resources that the smaller, more informal groups were not always capable of committing. This is problematic, given that the small groups often serve rarer conditions that are particularly vulnerable to misinformation and misunderstanding because their conditions are unknown to many GPs and consultants.

The work of developing lay-accessible routes to expertise cannot be disentangled from the work of furthering biomedical research and policy activism. A membership base that can articulate their symptoms and rights will be more effective in attempts to access appropriate treatment and care. When a patient organisation surveys a population about their experiences, those surveyed are exposed to technical language, and asked to reflect on their experiences and frame them in ways more readily accessible to biomedical production professionals and in appointments.

“People with moderate-to-severe eczema sometimes find it difficult to be referred to a specialist. They can feel trapped. We give them keywords to use in the appointment that will move things on.”

Staff Member, Eczema Outreach Scotland

Patient organisations do not just translate information from the professional sphere to the lay,

but enhance the exchange of information between expert peers. There are many skills involved in living with a medical condition. Managing a complex regime of treatments and reams of medical information, recognising signals from one's own body, self-injection, physiotherapy regimes, making judgements about when to seek additional medical attention all need to be learned. Health problems often affect everyday tasks and experiences- there is skill in opening a bottle with arthritic fingers, getting a child affected by painful rashes to sleep. Forums, social media platforms, face-to-face meetings, peer-support groups and conferences all provide means of exchanging expertise. As information becomes more complex and technical, the process of checking it for veracity and safety becomes more resource intensive. This leads to difficult choices.

Bureaucratic and organisational hurdles to accessing care and support also require skill to navigate. Systems of distribution may involve moving between health and social care, charities, national and international groups, drawing on rights enshrined in complex legislation, building relationships and keeping documentation. The complexity of this work is compounded as people with the same health problem may face different challenges and opportunities depending on their location, age, income and other demographic features that factor into eligibility. As with biomedically-focused information, information is often delivered in holistic narratives combining clinical, bureaucratic and emotional content. Advice on accessing respite care might include reference to relevant legislation and complaints procedures, and pre-emptive empathy advising that the experience is likely to bring a carer to tears.³⁰

Challenges and opportunities for development:

- Patients are not homogenous or static; information needs vary hugely between individuals, and over time as individuals gain expertise. Few patient organisations offer routes to deep understanding of the biomedical roots and latest research of conditions. Even as academic resources are opening up, the volume of material becomes ever more overwhelming. Peer to peer learning through open MOOCs show the potential of groups to develop and coordinate expert curriculums.
- Tools that collect and distribute patients' expertise in the daily challenges of living with health problems such as Patient Innovation³¹ have huge potential. Vibrant communities sharing experience exist online, particularly on YouTube.³² Patient organisations seeking to maintain an authoritative voice and to protect their members from misinformation must balance encouraging this exchange with safety concerns. Systems that support this work could be enhance efficiency and enable the sharing of more in-depth knowledge.

My story

A ubiquitous feature of organisations' intelligence exchange offerings, from the very youngest and smallest to the oldest and largest is the sharing and centring of the experiential narratives. Narratives often accompany more formal biomedical, bureaucratic or practical information. Life stories and descriptions of specific events, encounters and treatments are key multi-purpose tools. They raise personal experience to the level of evidence, providing a meeting point between biomedical information and lived experience. They offer readers affected by the condition a sense of shared experience, and educate unaffected readers about the lived experience of a condition, empowering the writer to define their experience. These narratives typically take a holistic, experiential stance, in which physical discomfort, emotional states, personal relationships and responsibilities are integrated with biomedical details. In accounts of treatment seemingly minor inconveniences and social interactions with clinicians are granted as much reality and prominence as technical details. Narratives are regularly deployed in policy activism and public education, and are particularly powerful in fields which have relatively small pools of data to draw quantified data from, such as rare diseases.³³

There are several platforms designed to share written, audio and video narratives of patient experience; Healthtalk, a project by DIPEX and Oxford's Health Experience Research Group is one example.

Challenges and opportunities for development:

- The narratives shared online are usually presented as text based stories or video interviews. They represent a huge store of information which could be rendered more accessible and usable to both human readers and analytics systems.
- While much of the power of narratives comes from their holistic, experiential angle that, systems that could suggest or identify patterns could be hugely powerful.
- Aggregating stories across platforms and organisations would offer an opportunity for extending the information base.

ENVIRONMENTAL FACTORS

Patient organisations have long used the tools available to them to deploy collective intelligence against the complex challenges that their members face. A series of interdependent technological and cultural changes have altered the environment and incentive structure within which health care happens in ways that make an analysis of this work particularly relevant now. These changes are complex and heterogenous, deeply entangled in other technological, cultural, and economic development.

For our purposes the most important factors are the huge changes in the amount of data available about individuals and conditions, the rise of personalised medicine, increasing public access to research, changes in institutional attitudes to patient's self-education, and changes in public attitudes to data and to self-management.

The development of new tools and techniques to discover, track and analyse biomedical data have opened up vast new avenues of investigation to discovery and management of health problems. Rare diseases are more often identified, and common conditions are stratifying into subtypes and individual presentations.

Big health data

The costs of producing, collecting, storing, accessing and processing data have been falling exponentially for decades, opening up many new potential perspectives on individuals, institutions and corpuses of knowledge. Given a definition of 'data' as reusable, accessible information, 90 per cent of the data in the world in 2013 had been created in the previous two years and much of the information produced in this 'networked society' is about people. Much of this is the previously invisible information about our lives and from increasingly sensor-rich mobiles and wearables, the cookies on our browsing, the tracking of our purchases, diets and activities.

Mayer-Schönberger and Cukier explain that the promise of 'big data' is that there are *"things one can do at a large scale that cannot be done at a smaller scale."*³⁴ These 'things' including mining for patterns, identifying and quantifying risks and opportunities, predictive modelling and the acquisition of real-time information. Under such analysis, the performance and management of health is fundamentally altered.

Sensors of many kinds equipped with connectivity and processing power have become more powerful, cheaper, and more compact, enabling the development of ever more convenient and comprehensive health tracking systems. Signals such as heart rate and blood glucose level can already be measured constantly and non-invasively. Meanwhile developments in diagnostics have opened up vast new reserves of biomedical information. The cost of sequencing genomes has plummeted - a full genome that cost \$100 million in 2001 by 2014 cost less than \$1,000 - less than a chest x-ray. Molecular diagnostics are bringing new discoveries in proteins and other biomarkers. Equipment that can measure body fat percentage, blood pressure and other signs are moving into homes, providing more intimate portraits of individual bodies. These are always understood in the context of analysis of on the mass data of the wider population.

Big data analytics relies on complex digital systems and expertise that patient organisations are not usually able to keep in-house, but the impact on their work is enormous. Patients' bodies and lives may now be transformed into valuable data resources that private and state actors want to bring within their store of analysable information. As common diseases stratify the claims of one large patient organisation to speak authoritatively for all those affected may come under question. As more aspects of health are quantified, and the management of risk is increasingly important, ill and well become points on a spectrum, rather than a binary.³⁵ The plummeting cost of both diagnostics and data management have brought much of this field into profitability and summoned a host of new private offerings of platforms and tools for individual self-tracking, for patients sharing and comparing data, and data collection by healthcare systems.

However, social attitudes and legal protections of health information are particularly complex. Patient organisations can have pivotal roles in convincing patients to collect and donate data and negotiating protections for collected data. Private companies can find that navigating these strictures while permitting innovation and research is a complex task. State actors and private actors can clash, as when the FDA banned 23andMe from advertising its claims to identify specific medical conditions in 2014.

Open-source and collaborative work does exist, but is often led by self-selected experts. Patient organisations, motivated by problem, rather than interest, have been running co-operatively owned biobanks and registries in the US for some time, in part as a response to the blocks to research they encountered when trying to support work with privately-owned equivalents.³⁶ These efforts to distribute the burden and benefits of the work of gathering and analysing vast amounts of information are pursued with close attention to the rights and involvement of the people whose bodies provide the information.³⁷

In an era of datafication, the work of collectives to haul information between domains becomes more urgent. The collection and standardisation of health data can be used to control which health experiences and outcomes are considered credible, valuable, or even real. As more data is collected, and more evidence produced, experiences which fall outside of that evidence may be dismissed – but the production of such evidence is difficult.

Computerization allows more aspects of life to be scrutinized, quantified, and analyzed for their relationships to health and disease... The safety and efficacy of specific protocols and treatments are assessed based on data from very large populations of patients and providers across time and space... insurance companies are already moving toward covering only those procedures demonstrated as 'valid' through such standardizing research.³⁸

Collectives offer other routes to credibility and the recognition of individual experience that do not readily fit into a datafied vision of the world.

Shifting relationships with information

Lay expectations of access to medical information and a more central role in decision-making have changed dramatically in recent decades. The internet, and the push for open-access publishing within academia, initiatives including pubmed, have opened up large sections of libraries and recent research to laypeople. It is important to remember how recent this practical change is, to contextualise the scale of culture change taking place alongside. In his E-patient paper Dr Ferguson recounts anecdotes of taking patients to the Yale medical school library and being turned away as *“any patient seeking library access was probably just gathering information for a malpractice suit.”* He recounts similar examples of doctors and librarians deliberately blocking access as late as 1994.³⁹ Patients interviewed in our ethnography of Lupus sufferers reported stark differences in doctors’ attitudes. They reported that one of the most valuable pieces of information shared in peer-support meetings was comparison of their consultants’ attitudes to patient’s knowledge. Finding a consultant who would listen to them as expert patients and take their opinions, evidence and analysis into consideration while negotiating treatment options was a high priority.

Even with supportive clinicians, the clinician/patient dyad is not a consistently successful site of implementing shared-decision-making.^{40, 41, 42, 43} Doctors and patients are repeatedly found to leave appointments with very different views of the discussion that has taken place.

Clinicians who want to engage with patients’ expertise face significant barriers. Whilst the NHS has made ‘engaging, empowering and hearing’ informed patients a key goal⁴⁴ the time allowed for these more nuanced negotiations has been cut. Yet clinicians remain legally responsible for prescribing decisions, no matter how much research a patient brings to that decision. This responsibility weighs heavy. GPs in particular report a need to practice ‘defensively’ in the face of increasing rates of litigation.^{45, 46} Legal concerns are further complicated by inconsistent local and institutional rules regarding data-sharing and decision-making, muddled further by misconceptions.

“*My own doctor has always been supportive in making me independent—he helped me learn to inject myself for instance. But when I asked to see my records he said ‘I can’t give you your own record because of the Data Protection Act’. That was a misconception but it’s a very common one. A lot of what we had to do at first was curing the scars of legal misunderstandings.”*

Mohammed Al-Ubaydli, Patients Know Best

SUSTAINING COLLECTIVE INTELLIGENCE IN PATIENT ORGANISATIONS

Generally, collective intelligence refers to the process by which large groups of individuals pool their knowledge, data and skills to contribute in solving societal issues. The term is frequently invoked in relation to the internet as networked publics participate more systematically in the production of large bodies of knowledge such as Wikipedia or open-source software. By inputting environmental or clinical data, mapping territories, discussing and voting, coding and writing, citizens can contribute their knowledge and ideas to data collection tasks, analysis and public debates. Collectives are using the distribution and communication capacity of digital technology to collaborate on an unprecedented scale and by doing so produce extremely complex forms of knowledge. Groups that contribute and collaborate in this way, also increase their overall understanding of the domains they participate in and act more effectively.

Patient Organisations increasingly fit in this category of collaboration. One of the most powerful functions of Patient Organisations, as we have seen above, is to collect, update, store and distribute information about a condition. It is reasonable to argue that the development of internet tools has facilitated the circulation and access to various bodies of knowledge on a wide range of conditions, thus raising scientific literacy. Online communities of patients and activists have rapidly multiplied, some of them discussing credentialed knowledge and comparing them to people's narratives,⁴⁷ and even becoming epistemic communities on their own.⁴⁸ Beyond online forums, many 'classic' patient organisations, users' and activists' groups also engage in a reflexive work on knowledge, know-how and experience, staging, weighing up, sorting, assessing, and reordering heterogeneous sets of information and data on the conditions and health problems they are concerned with. They take advantage of the internet to launch surveys in order to better represent concerned people, constitute virtual libraries to be put at public disposal, and develop content in various formats in an effort to adapt their heterogeneous audience.

However, not all internet systems, have the capacity to support collective intelligence. In fact, many patient organisations use systems that were not particularly developed for the health domain or for organising knowledge coming from multiple sources and stakeholders. The smaller organisations in particular, rely on generic platforms for content publishing or social media components for communication and exchange. Many of these systems are excellent for publishing and circulating material and enabling conversations but have limited capabilities for aggregating data or structuring discussions. This constitutes a challenge and a significant opportunity for innovation. In other domains of civic life, over the last few years, we have seen numerous failed attempts to generate 'collective wisdom' by bringing together citizens on loosely designed discussion platforms. Public forums to discuss policies, budgets, health or other crucial topics often fail to generate the collective creative output that we witness in open source development or Wikipedia. Often these forums simply offer text boxes where individuals can write opinions and reply to others, with limited functions for storing and grouping the discussions. In these systems the burden of co-ordination and synthesis is on the participants and it comes as no surprise that participation is low, information repetitious, and organisers find it impossible to synthesise the discussions.

The challenge for digital environments that support collective intelligence and collaboration, is to offer objects on which it is possible for participants to jointly operate, by providing visualisations of the common results. Systems that support collective intelligence need to make tangible the 'whole' emergent results. Forums often offer exactly the opposite, and highlight the individual contributions, the parts or fragments. By not providing a sense of the emerging collective output they inhibit the creation of the collective itself. From these experiences what we can learn is that for digital systems to become components of the collective extended mind and foster collective intelligence, they have to have some characteristics. These characteristics include the possibility to modify the tools, aggregate the contents and contributions, retrace the history, visualise the aggregations and the single elements, include analytic tools and allow the negotiation of terms. In other words the systems should support learning and metacognition through synthesis and modification mimicking the process of cultural evolution.

KEY RELATED INSTITUTIONS

The Information Standard

A key tension in patient organisations seeking to engage with politics and publics is the degree of authority that messaging should have – the ideal would permit speaking on the national stage but not erase lay members experiences and voices. Credentialing structures that permit information to be more authoritative and effective within large bureaucratic regimes can throw up barriers to participation. Many large UK charities have decided to commit to the Information Standard. This is a certification programme administered by NHS England which assesses the processes by which information is produced against a standard of being *“clear, accurate, evidence-based and up to date.”*⁴⁹ There are three independent organisations who are authorised to carry out the assessments and offer certification against The Information Standard. These are EMQC, G4S Assessment Services, and the Royal Society for Public Health. Information producers who pass the assessment process are allowed to use the IS quality mark on all of their materials, which eases the process of spreading information through some routes controlled by the NHS, such as leaflets disseminated by doctors or in waiting rooms. The IS is an attempt to help laypeople determine the quality of the information they are accessing outside the NHS’s immediate purview, thus enhancing the collective level of medical knowledge of the population.

While the accreditation and processes are powerful tools, they complicate the process of engaging with information and ideas provided by lay patients and carers. Smaller charities with resource constraints also struggle to follow the accredited processes required by the Information Standard, meaning it can function as an additional barrier to the dissemination of information about rare diseases, local issues or under-resourced areas.

James Lind Alliance

Many charities including Stroke Association, Diabetes UK, Alzheimer’s UK and others that make significant investments in medical research work with the James Lind Alliance to identify and prioritise research gaps. Priority setting partnerships take around 18 months of surveys, consultations and workshops. They include survivors and carers, healthcare professionals including GPs, specialists, nurses, and researchers. The effort often entails a one-off realignment of the charity’s research priorities built on a carefully moderated consensus that brings in the intelligence and energy of a wide network of patients and experts. Because the top ten list of priorities are produced in a formal process they are accepted into NICE’s Database of Uncertainties about the Effects of Treatments (UK DUETs). Major funders refer to this list when deciding what to endorse, so the effects can be felt beyond the originating organisation.

CURRENT COLLECTIVE INTELLIGENCE PLATFORMS

Although the available examples of digital systems for collective intelligence in the field are still limited and fragmentary, there are increasingly attempts from private, charitable and state actors to develop platforms and systems for the purpose. We have classified the systems in for-profit and non-profit platforms, but in reality distinctions are complex. Patients Like Me, a profit-making company that advertises a 'not-just-for-profit' attitude, was founded by the brothers of a man with ALS hoping to accelerate the hunt for a cure, and partners with charities such as AKU society. Chronology, whilst a not-for-profit founded by a patient, is part of the Silicon Valley accelerator ecosystem graduates of the y-combinator programme. Health Unlocked, a profit-making social platform was founded by a patient and makes its profit by providing a service to the NHS.

Private platforms

Health information is valuable to private enterprises for many reasons – mineable data can enhance discovery and optimise current practices, tools for self-management can attract interested users to a platform. In cultures which prize health and perceive health maintenance as a moral duty, the market for health information services extends beyond the ill to the conscientious well. Data management tools and accumulated data can be an attractor to an ecosystem than may include wearables and sophisticated equipment as well as well as platforms. In 2009, Swan⁵⁰ described more than 20 major platforms supporting information management and exchange used by people with a variety of health conditions. Most of the platforms promoted social features which included peer-to-peer emotional support, 30 per cent offered physician Q&A, and a select few integrated access to clinical trials or to quantified self-tracking. Since then more examples have emerged and existing players have grown userbase and features. The most famous dedicated platform is probably PatientsLikeMe, developed in the US, but the market includes the France-based Careny.

The plummeting price of genetic sequencing has enabled platforms which centre around diagnostics rather than specific conditions, such as 23andMe. Several companies, including Withings, provide an ecosystem of devices including measures of weight, body fat percentage, pulse, blood pressure and sleep, all of which can be tracked and shared. A few companies such as uMotif use the capabilities of smartphones – such as accelerometers – to perform simple diagnostics integrated with results from quizzes, timed games, etc., to measure symptoms.

Despite their differences, most of these platforms share with many internet businesses the attempt to create two-sided markets – i.e. economic platforms having two distinct user groups that provide each other with network benefits. One market is the patients, and the second one is the public or private research sector. Generally speaking therefore, these companies have a clear interest in keeping the two user groups separate to ensure their existence as mediator.

They have two key means of encouraging patients to contribute data. Firstly, the promise that using the platform helps individuals to better manage their health by revealing patterns, improving their records and potentially their interactions with the healthcare system. Secondly, patients are assured that participation will allow research to progress in such a way that it will ultimately benefit them. This motivates companies to publicise their involvement in research: in 2012, PatientsLikeMe had 25 authored papers published in peer-reviewed journals and 23andMe a handful of research studies published in journals such as *PLoS Genetics* and *PLoS One*, one of them discovering two new genetic associations. Communicating to patients about these research results is a clear strategy in order to motivate their participation in data collection.⁵¹

The features on offer are often attractive to patient organisations that wish to consolidate information and communities. Many private platforms encourage patient organisations to bring in their pre-existing communities by providing tools to establish and manage communities on their platforms. This collaboration can be very productive, though it raises questions of data ownership, and communities' activities are constrained and made vulnerable by the private platform's developments – much as they are on other social media platforms.

PatientsLikeMe

www.patientslikeme.com

The PatientsLikeMe platform is a “*health information sharing site for patients.*”⁵² Users are encouraged to input data about their medications and symptoms, environmental triggers, etc., over time, providing an ongoing journal. There are features enabling and encouraging them to connect with others, share and compare data and discuss their diagnoses, medications and symptoms with one another. The company makes its profit by selling aggregated, de-identified data to commercial partners, such as pharmaceutical companies and medical device makers. They also charge those running clinical trials for reaching out to users, but provide information to academic and charitable institutions free of charge.

As has been discussed previously, the work of translating information from experiential reports into quantified, minable forms is difficult, labour-intensive, and costly but the results are potentially hugely valuable. PatientsLikeMe's system distributes the burden of this work between users and staff. When inputting their health data, users are presented with a list of symptoms to choose from. If they cannot find a pre-existing entry that satisfies them they can submit a new symptom manually. Staff manually review every new entry, either merging it with pre-existing symptoms, or creating a new category. To permit data mining to work on multiple levels – from broad symptom categories to the granularity of individual descriptions staff then ‘map the patient-generated symptom categories to expert classifications in hierarchically structured terminologies’ manually interfacing between colloquial terms and clinical knowledge.⁵³

PatientsLikeMe is funded by companies wishing to use their data to undertake research, so a lot of feature development and investment is directed by funded projects. But they do partner with patient organisations – AKU society has negotiated a partnership to create an open global registry of patients. Some of their in-house research is done at the behest of members: a first study on the effect of Lithium on ALS patients was undertaken by 348 members of PatientsLikeMe on the suggestion of one of them. Drawing on its result, PatientsLikeMe researchers conducted an observational study which has been followed by a traditional randomised study.⁵⁴ There are many examples of studies being run with data and surveys from members this platform.

“Using a cohort of 513 members of the PatientsLikeMe MS community, a team of researchers identified significant worsening of symptoms associated with menopause, particularly for those women who had undergone surgical menopause or were younger at the onset of menopause. Use of the MS Rating Scale, Revised (MSRS-R) helped to identify MS symptoms such as vision issues and arm function that do not overlap with symptoms of menopause.”

PatientsLikeMe

PatientsLikeMe has a French equivalent, Carecity, now established in France, Germany, Italy, Spain and UK. Carecity's business model is slightly different: they sell the access to the patient communities in order for companies to perform surveys or polls.

23andMe

www.23andme.com/en-gb/

23AndMe is another well known platform. The company offers customers DNA analysis based on saliva samples. This information is (where permitted)⁵⁵ translated into risk factors for inherited conditions, responses to certain medications, physical features and ancestry tracing. The user is also encouraged to join the online community to discuss findings, to share personal health data and phenotypic data, and participate in surveys. The company plans to map genetic information against information provided in surveys to produce research breakthroughs (e.g. the identification of genes involved in certain pathologies or which alter the effects of treatments). A number of platforms have emerged that build on 23andMe and similar services. Genomera is a platform for group health science, providing users with the tools to create and participate in their own clinical trials⁵⁶ with *“revenue expected to come from test referrals, sponsorship and advanced analytic services.”*⁵⁷

uMotif

www.umotif.com

uMotif provides software for self-management and information sharing and decision-making between doctors and patients with long-term conditions such as Parkinson's, diabetes, renal, rheumatology and post-operative care and rehabilitation. The platform takes inputs from devices such as blood pressure monitors, an accelerometer functioning as a sleep and movement tracker and cognitive testing games to help translate patient experience over time *“from the qualitative to the quantitative.”*⁵⁸ The stated aims are to assist in communication between individual patients and doctors, to enable better self-management through medication reminders, opportunities to input, track and learn from data. They also hope to amalgamate information for research. They worked with Parkinson's Movement and The Cure Parkinson's Trust to develop an app which tracks many data points, including their own wearable and integration with other companies' such as FitBit and Withings. This app was the first to be prescribed by the NHS.⁵⁹ They formed a network of individual patients, patient organisations, private software developers and state healthcare. The app does not provide space for individual patients to directly connect and compare data, and focuses on improving the efficiency of the patient's twice-yearly appointments with their Parkinson's consultant. Lessons can only be learned by the patient about their individual data, or by researchers about amalgamated data - there is no space for feedback or collaboration between patients.

Crohnology

crohnology.com

Crohnology is a platform developed by a patient with Crohn's that permits patients to share data about the effects of treatments and self-experimentation on their symptoms of Crohn's or colitis. Users build a timeline of their health cross-referenced with treatments, including medications, surgeries, self-experimentation with diet and activities such as stress-relieving workshops or exercise regimes. The aim is explicitly to leverage numbers of experiential reports to "create a body of evidence around treatments." They ask patients to "contribute to collective knowledge" with the promise that "we share the knowledge back with everyone."⁶⁰ The developers are graduates of startup accelerator programmes and as of June 2015, the platform is in public alpha.

“I started Crohnology because after living for Crohn's for 14 years, I realised that the data that I was gathering outside the doctor's office was just as important as, if not more than, what I was learning inside... I believe patients are the most valuable part of their care. I believe they walk around with great silos of knowledge and information that is of uncountable value to the medical system and to other patients. And, from my experience, I know these silos go completely untapped. It is necessary for us to be connected to find a cure.”

Sean Ahrens, Chronology founder

Non-profit platforms

Not-for-profit platforms are much more likely to be single-purpose than private platforms, most likely because they are often developed by charities with limited funds, or with funds allocated for specific projects with narrow aims. Without the promise of returns, there is less incentive and thus investment in drawing a wider range of patient information into an ecosystem of platforms and devices. This fragmentation leads to duplication of efforts and dispersal of patients.

RareConnect

www.rareconnect.org/en

RareConnect is an international platform for rare disease communities developed by Eurordis and NORD. Established patient organisations contact the site managers to request permission to set up community pages – these pages then have learning resources, a moderated forum and a space for patients to share their stories. National patient organisations can create a profile connected to the community with contact details, and provide moderators for the forums, hoping to cover the multiple languages. Individual patients are permitted to share their story and start discussion threads and can post questions to the community's webmaster who according to the FAQ will "put it to the specialists who have agreed to answer your questions from time to time."⁶¹ There is no attempt to translate this experiential information into quantifiable forms, or to collect the resources and explanations patients offer one another in forum threads into more coherent, searchable and usable forms.

HealthTalk

www.healthtalk.org

HealthTalk is a platform developed in partnership between a charity DIPEX and the Health Experiences Research Group or (HERG), a research group from Oxford University. It collects video and text narratives from patients, explaining “*what it is really like to have the disease.*”⁶² Experiences are represented on a timeline through early stages, diagnosis and treatments, to reflections on the entire experience. For each condition represented on the site, about 40 to 50 patients have been interviewed by a team of researchers and their interviews filmed or audio recorded. The patients are chosen to represent a range of ages, socioeconomic statuses, ethnicities, genders, disease stages etc.

healthtalk.org provides free, reliable information about health issues, by sharing people’s real-life experiences. You can watch people sharing their stories about cancer, autism, motor neurone disease, pregnancy, drugs, depression and much more.

If you, or someone you care about, is affected by any of the 85 subjects we cover, you can find out what happened to 40 other people in the same situation. You will find good advice and reassurance on topics such as:

- Making decisions about health and treatment
- Talking to friends and family
- Practical issues like money and travel
- Emotional wellbeing
- Impact on work or education

Healthtalk website

Reg4All

www.reg4all.org

Reg4All is a platform developed by Genetic Alliance, a US-based non-profit, in association with Private Access, a US for-profit privacy technology company for patient organisations to manage registries and biobanks of members. It collects data using surveys. These are either a generic survey, or one designed by a patient organisation to collect health information. This survey is usually completed only once, and is very in-depth. While users are able to see other respondents’ answers to questions, it does not provide individual users with either social features or the chance to track data over time. The platform’s messaging places particular emphasis on the strength and flexibility of privacy controls.⁶³ Whilst there is a generic survey which anyone with any or no diagnosed condition can complete, the platform is optimised for patient organisations to design condition-specific questionnaires. The main objective of the platform is to constitute a knowledge base including the identification of patients in order to facilitate research activities and clinical trials.

Analysis of the platforms

As these cases show, when building platforms to support groups in their process of constructing environments to foster learning and collective intelligence, the challenge is not only to create settings for sharing and communication, but also to provide the **means for knowledge to be made public, to be assembled, sedimented and reflected upon**. It is not enough to give a space, build a zone of interaction as can be found in patient forums. These are important arenas for discussion and support but they rarely allow for the real integration of experiential and clinical knowledge.

In the examples above, different organisations are exploring different modalities of sharing knowledge. HealthTalk has put considerable effort in making videos of sufferers and carers to convey experiences and emotions while Chronology provides aggregate data in the form of bar charts and ratings. Rareconnect aggregates documents and people while Umotif and PatientlikeMe graphically display charts, timelines and various representations of different measures. The curatorial efforts are spent in organising and assembling information in an effort of sense-making. The aggregation of data, the comparison of treatments, the visibility of evidence and research are just a fraction of what would constitute a knowledge system that could allow patients to be active participants in the construction of a health commons.

This requirement has implications both for the design of digital solutions and for the organisational models. Any reflection on the governance models to sustain processes of collective intelligence should therefore consider what are the legal, economic and administrative requirements for an open and reusable system of knowledge creation and sharing which recognises the multiple entanglements of knowledge systems.^{64, 65} The ongoing battles around biomedical data, patient records and privacy are part of a crucial debate on the mechanisms that ensure that collective intelligence can in fact emerge. They constitute a good example of why governance models are part of the prerequisites for effective collaboration.

CASE STUDIES

AKU Society

Registered charity	2003
Paid Staff	5
Volunteers	N/A
Income 2013/2014	£424,636
Charitable expenditure 2013/2014	£350,574⁶⁶

Alkaptonuria (AKU) is a rare genetic disease causing early onset osteoarthritis that affects around one in 250,000 people. Those affected typically have brown or black urine from birth, so are often diagnosed in infancy. The symptoms osteoarthritis appears in an affected person's 30s or 40s and over a lifetime most sufferers will have multiple joint replacements. Around 80 people have been identified as suffering from the condition in the UK.

The AKU Society was founded in 2003 by a patient, Robert Gregory and clinician, Dr Ranganath. They were soon joined by Nick Sireau, the parent of two boys with AKU. This small group possessed a fortunate set of skills and relationships. Also, unusually for a rare disease, there was a basic understanding of the faulty metabolic mechanism behind the condition and a drug known to affect this mechanism. Dr Ranganath was passionate about the project of creating a centre of expertise in AKU within the NHS, and had strong pre-existing links to Swedish Orphan Biovitrum International (Sobi) who held the license for Nitisinone, the drug believed to be a potential treatment for AKU. Nick Sireau had postgraduate qualifications in management and collective behaviour, and years of experience as founding CEO of Solar Aid, an international non-profit. The group effectively leveraged their skills and connections to secure funding and bring patients and experts together for an ambitious programme of research over the society's short history.

From the start, the AKU society worked at collecting and deploying intelligence in a network that brought together patients, the NHS, businesses, and other national and international institutions. In 2006 when a society member donated her body to science, the society raised money to fund an autopsy. They then secured £500,000 from the Big Lottery Fund to develop an animal model. The society supported the campaign within the NHS for a centre of excellence by commissioning an accountant to deduce the cost to the NHS of a single AKU sufferer (which because they will have multiple joint replacements, can run into millions of pounds). In this National AKU Centre (NAC) patients are treated with off-label Nitisinone.

The society also runs an international consortium of hospitals, pharmaceutical companies, biotech companies, universities and national patient organisations called DevelopAKUre. This consortium received £8 million funding from the EU for a clinical trial programme comparing patients treated with Nitisinone against a group of non-treated patients drawn from across continental Europe. They supplemented this funding by drawing on their members' personal networks and the crowdfunding platform IndieGoGo.

“If we didn't have the society what we have done in seven years would have taken thirty.”

Dr Ranganath

The group works hard to find and involve AKU sufferers in their activities. At the outset the group knew of only five people in the UK with AKU. Faced with the need for additional evidence for research the society sent 16,000 information packs to GPs and identified 80 new sufferers in the UK. They built strong connections with sufferers to make them aware of all the ways they could contribute to research and convince them of the worth of making such commitments. People with AKU who attend the NAC are asked to fill in detailed surveys of symptoms and invited to visit the centre of expertise once a year for five days to undergo a series of tests, to provide samples of bone removed in surgery, to contribute time and money, and physical risk to ongoing clinical trials in new drugs which require continual adherence to a challengingly strict protein-controlled diet. Those involved in the clinical trial must also regularly travel to Liverpool and undergo testing.

For healthcare professionals, specialism in rare disease can be an awkward fit in current clinical and research career pathways, so the society has worked hard to build a network and provide incentives and support. Commitment to research in a rare disease field carries risk as funding and support is more unpredictable than it would be in an established field such as cancer. Initially Dr Ranganath had to take unpaid leave from the NHS to work with the society on establishing the centre of expertise. The centre now provides a hub for support and materials that benefit researchers. The society works to provide other incentives that benefit researchers such as running conferences and arranging for special issues of journals, bringing patients willing to be tested and studied from across the UK and Europe to where the researchers are.

“We've been collecting samples from patients when they get joint replacements. We need a relationship as the patients need to know that we want those samples and that they need to get in contact with us when they know they're going to surgery, so we can prepare.”

Dr Ranganath

Both the clinicians and patient organisers credit the speed of progress to mutual commitment to sharing information, and the dedication of the other side.

“The connection with patients is our great strength. They have access to all our research. So they understand more and are better communicators. When the patients see their voice is being heard, they're more involved, more willing to travel to us, give samples etc.”

Dr Ranganath

“We have been able to set up a particular culture of transparency, of sharing – researchers have told us this is the most enjoyable project they've worked on, which allows us to get further with few resources. People are very committed because of that.”

Nick Sireau

The group uses a number of dedicated commercial platforms to collect, manage and disseminate sufferer's biomedical information. Society members with AKU are encouraged to use PatientsLikeMe to track, share, and discuss the progression of their symptoms. The records of those who attend the NAC, including results from their five days of annual tests are stored on the Patients Know Best platform. The patient is able to choose to share these test results and their entire medical history with their local GP and their various consultants, and bring the Liverpool-based AKU specialists into conversations about treatment decisions.

The society's efforts to educate target both patients and clinicians. Patients are invited to regular face-to-face workshops which update them on the progress of the research, provide practical advice in areas such as navigating state support and managing mental health with long-term pain. The society partnered with the Royal College of General Practitioners to develop an open-access online learning module aimed at GPs. Together with the consolidation of patient records from disparate specialists in the Patients Know Best platform, this gives GPs who have a patient with AKU a clear route to necessary biomedical information for complex treatment decisions. These efforts to educate both patients and GPs and make information and consultations with specialists available to both enable them to make better-informed treatment decisions. It also equalises access; previously the quality of care could depend on the patient's ability to explain their condition.

The society contributes to campaigns and research on policy change and the international stage through membership of umbrella organisations including Genetic Alliance UK and EURORDIS. Members often speak on patient-centred research and intend to support other groups in developing virtual centres of excellence, in part because they recognise the need for AKU expertise extends beyond the region that can be served by Liverpool University's National AKU Centre.

Eczema Outreach Scotland

Registered charity	2011
Paid Staff	7
Volunteers	20
Income 2014/2015	£204,639
Charitable expenditure 2014/2015	£173,326 ⁶⁷

Eczema Outreach Scotland is a young charity set up by the parent of a child with severe eczema that employs seven staff most of whom have direct experience of eczema or of caring for a sufferer. Their focus is not on biomedical research into a cure, but improving daily life for affected families, as outlined in their stated aims.

- **Support and empower families** through the provision of practical information, emotional care, networking and project-based activities.
- Increase the **confidence, self-esteem and self-management skills of children and young people** thus enhancing their long-term **health and wellbeing**.
- **Reduce stigma and improve understanding** of eczema by raising awareness of the condition in local communities.
- **Influence policy** to improve services for families of children with eczema.

Eczema Outreach Scotland, 'Our Aims' Annual Report 2014/15

Eczema is a common condition that causes the skin to become dry, itchy red and cracked. Around one in five young children in the UK will develop it. Most cases are mild but over 80,000 children and young people under 18 suffer from its moderate to severe form. The condition is not life threatening or degenerative and is usually self-limiting with long periods of remission. In many cases the symptoms have specific triggers, the most common being certain foods, chemicals, stress, weather or clothing. In its moderate to severe form, eczema can have a huge impact on the daily life of the affected individual, causing pain and sleep disturbance, and is associated with increased anxiety and depression. Eczema Outreach Scotland focuses on those severely affected by the condition and currently supports 370 member families.

Families who join receive a personalised welcome pack with age-appropriate therapeutic toys and resources for affected children and their carers. The whole family is then supported through phone calls, emails, home visits and other one-to-one help. Children are invited to join self-management clubs with games and events.

“*We all felt privileged to be part of this EOS event, especially my son, whose eczema was for once responsible for a positive and enjoyable experience.*”

'Julie', A Family's Journey with Eczema Outreach Scotland

Eczema Outreach Scotland provides many ways for member families to connect with one another. Local peer-support groups and larger learn-and-share events are supplemented by an active Facebook Group. The relationships that develop between peers provide routes through which empathy, practical support, and information can be exchanged. They also build

members' confidence, empowering them in their efforts to push for better support for their children from the healthcare, childcare and education systems.

“The people we support often have head to toe eczema: they're up all night bandaging the child and they're putting on creams for hours many times a day. They get tired of hearing others say “my kid has eczema too” when for those people it's just a small patch that's itchy once a week. Connecting these families with peers is important; they get a lot out of just being understood.”

Alison Sweeney, Eczema Outreach Scotland

Eczema Outreach Scotland's members are brought into the heart of decisions regarding its operations and strategies through intensive consultation and evaluation work. Staff and board have experience of eczema or caring for an affected child, and members serve on the board. The organisation performs an annual survey of members, runs regular focus groups and interviews members regarding direction. Every member is contacted regularly throughout year by phone, email and newsletter, and most will be seen at events.

The organisation uses carefully structured systems of governance to effectively enhance members and professionals' collective intelligence in various workshop formats. The organisation works hard to develop relationships of trust and mutual benefit with dermatologists and dermatology nurses who contribute to regular 'learn and share' events. Maintaining this trust requires that professionals never feel pressured to provide specific medical advice outside of an official appointment context. They balance this concern with members' desire for information using a carefully designed workshop format. Members who attend are put into small groups with a facilitator to collectively produce and prioritise questions to put to visiting healthcare professionals. This structure ensures individual members cannot seek specific medical advice on their cases, but that broad concerns are addressed. This encourages in-depth discussion between members, and supports those who might be nervous about asking a question in public. The clinicians enjoy the fact that by providing information and confidence to patients, their interactions in an appointment context are more efficient.

In another example, the group developed a workshop format for members who were less comfortable discussing personal issues in standard peer-support settings. EOS developed practical workshops in which members collaboratively create educational materials. These groups run parallel to children's art workshops, and the art and campaign materials will be placed together in the schools of members' children. There are many effects on informedness and empowerment: adults share information and empathy and have a chance to 'vent', while children connect their eczema to a 'positive, enjoyable experience,' and the wider community is made more informed about the condition.

The group engages with various networks to improve the daily lives and longer-term prospects for members and other eczema sufferers. While the group does not undertake or fund biomedical research directly, they facilitate contact between member families and research organisations, train nursing students, and operate as the 'patient voice' in the UK Translational Network in Dermatology (UK TREND). They are involved in policymaking through participation in a cross-party skin parliamentary group. They draw on connections with pharmaceutical companies to distribute samples of different emollient creams so that families can experiment and find what works for them. At the moment, their work centres on intensive support through strong connections using phone and face-to-face meetings. However, they engage actively and creatively with digital tools that serve their members' needs such as educational online games for children, YouTube videos on practical tips, a vibrant online support group for adult carers and an active presence on several social media platforms. The group is primed to use any new tools appropriate to their aims as and when these become available.

Stroke Association

Registered charity	1963
Paid Staff	635
Volunteers	4,828
Income 2013/2014	£33,546,000
Charitable expenditure 2013/2014	£24,080,000 ⁶⁸

The Stroke Association is a large institution concerned with combating stroke in the UK. It funds long-term research programmes in the prevention, treatment, and care of stroke, runs awareness campaigns, and provides support services. The Association's work reaches an enormous number of people and is deeply entwined with state services. There are 152,000 strokes every year in the UK and there are about 1.2 million stroke survivors living in the UK. Almost 70,000 stroke survivors use the Stroke Association's Life After Stroke services and this continues to rise each year. These are designed and run by the association but commissioned and paid for by the state. Around 3,520 people participate in volunteer-led Stroke Clubs supported by the association, many of which also have official connections with local hospitals. In 2014 over 20,000 people contacted the Helpline team. The Association operates on a five-year research plan, and funds 11 per cent of the total UK spend on stroke research. Their flagship educational campaign, 'FAST' developed to educate laypeople in the signs of a stroke and appropriate emergency action was taken up by the NHS in 2009. All of the lay information, and the processes used to produce that information are NHS' Information Standard. The organisation is large and its work complex, so this case study cannot cover the whole of the charity's operation; it merely attempts to highlight a few examples of work that contribute to or align with models of collective intelligence.

As an established 'big charity' the association is able to leverage its assets, expertise, and relationships to support large, long-term projects that significantly affect research, policy, and services on a large scale. But the scale of the problem, of the charity, and of the projects it undertakes makes bringing stroke survivors and carers to the core of the decision-making process a challenge. Like most large charities they are limited by resource constraints, the capabilities of existing tools and the difficulty of developing new ones, the sedimentation of much organisational knowledge and past work in bureaucracy which, while supporting work also risks siloing knowledge. They face particular accessibility challenges, particularly in information dissemination and tools, because those affected by their targeted disease area are older (75 per cent of strokes happen in people over 65), have comorbidities (high blood pressure, coronary heart disease and diabetes are key risk factors) and may be affected by a varied, complex set of disabilities, including cognitive and communication disabilities.

“ We stipulate that people pitching for research grants must have consulted with stroke survivors, and there must be consultations throughout to keep things relevant to the interest of the patient.”

Stroke Association Staff Member

“It’s certainly a challenge to find the balance between the professionals and the survivors. Fortunately we have a fantastic content developer, who works to make sure that we don’t lose that accreditation while still bringing in stroke survivors’ perspectives. She’s worked with the assessors who give the accreditation to find a way through the dilemma.”

Stroke Association Staff Member

Publications

The organisation collects, curates and distributes information between lay members and professionals through a number of publications including *Stroke News* for lay people and the *Stroke Improvements Bulletin* for professionals. In the case of the SIP, the Association explicitly stepped in to maintain a tool that supports communication and collective intelligence within the professional network which would have been lost. In both lay and professional publications, biomedical research information is supplemented by practical and bureaucratic information – and for laypeople emotional and social information. The patient organisation structure permits the Stroke Association to draw in relevant expertise from across a variety of institutions and cultures, breaking through silos and providing individuals and institutions with appropriate, accessible information.

*“I write a magazine, *Stroke News*, where we turn the research findings into articles for members. We want to inform them of the impact their money has on research and of developments in the field. But a key challenge is finding research that’s pertinent now to stroke survivors. A lot of our research is early stage, so it’s not something they can feel hopeful about.”*

Stroke Association Staff Member

*“Our *Stroke Improvements bulletin (SIP)* goes out to professionals working in stroke, including GPs. It summarises the most relevant, pertinent research, and changes in services for doctors. It was run by someone else within the NHS, but then with the cuts, well, it would have gone so we took it on.”*

Stroke Association Staff Member

The Stroke Knowledge Centre

With over 600 staff offering a variety of services across various platforms and different locations across England, Northern Ireland, Wales and Scotland, the task of managing Stroke Association’s internal information resources is a complex, continual process. The structures which permit this complexity of work represent organisational knowledge accreted over more than 50 years. The Stroke Association is developing a platform, the Stroke Knowledge Centre, that consolidates information, circumventing the potential problem of silos developing within a diverse, distributed organisation.

The SKC is intended to bring together internal information and experience across 70 core topics. Each topic has a central page summarising the Association’s knowledge and stance on a topic. The task of summarising the Association’s knowledge and stance on topics is allocated to different roles and across regions to bring in a variety of perspectives – although all contributors are paid staff working for the charity.

Adherence to the Information Standard guidelines on accreditation makes it 'impossible' to make the platform a wiki editable by all staff. The designers recognise internal concerns that there needs to be a standardised and agreed process through which content is provided and articles produced. The need for consolidation and increased efficiency, the value of authority, and effective dissemination of a consensus message has, for now, taken priority. But staff are encouraged to comment on articles and discuss whether the content of the articles matches their experiences – the articles are then revisited and updated based on comments and other developments as part of a defined timetable for updates.

My Stroke Guide

Through surveying stroke survivors and carers the Association identified a series of unmet needs around information management and services. Patients were struggling with the information, from medication to appointments, understanding their condition, managing and tracking their recovery. The Stroke Association embarked on an ambitious project to create a system that would assist with this burden of information work, while enabling stroke survivors, carers and support staff to envisage and achieve larger goals and support empowered self-management.

From the start design of the service and tools was user-led, with input brought in from workshops, surveys, labs, and 100 product champions. Continual and close engagement with users was vital to accommodate users with a huge variety in disability– stroke can affect survivors' sight, dexterity, memory and language comprehension, creating significant challenges to user design.

The tool explicitly sets about the task of solving the mundane cognitive challenges of managing the movement of information and responsibility across the network of the patient, their healthcare team, their informal support network over time and over stages of recovery. By managing mundane tasks it supports individuals to take on more complex cognitive work such as setting longer-term goals, tracking information, strengthening connections with carers, and building a local support network.

The service, now in beta, now consists of an online forum, a goal-setting tool with sub-goals and the capacity to monitor progress over time, an appointment manager, a diary, a news section which summarises research developments and the Stroke Association's work, a simple forum tool, and an extensive library of videos covering a range of biomedical information, practical tips for managing disability, emotional support, information on accessing support and care, etc.

The system is designed to encourage a user to strengthen their own support network. It permits and encourages information-sharing by giving every survivor two additional logins– for a family member and a carer – who can follow and support progress. As well as deepening bonds, the system prompts users to expand their support network, connecting with other survivors online and in local clubs.

The data tracking and sharing functionality is relatively basic – daily progress towards goals and steps can be tracked using a single star rating. The priority is to understand and develop the cultural change that means the tool's tracking function is used effectively by survivors and integrated in the practices of their care co-ordinator, physiotherapists and carers. The team also report awareness of, and ambition to, incorporate digital patient records. They are reluctant to invest in integrating with available private platforms, despite their impressive functionality because they are 'waiting for a national lead'; they cannot risk resources on adopting a solution that the NHS does not continue to support or is not adopted nationwide.

An issue that emerged early on was that those survivors who self-selected for involvement tended to be quite far along in the recovery process and less disabled. The project leaders realised it was vital to engage with official healthcare networks to access a representative sample of patients and problems. Seeking a commission from the NHS while the system was still in early beta drew officials and a broader set of patients into the network contributing intelligence to the development and design of the tool.

Other intelligence exchange

A key way the organisation brings in information about the concerns of stroke survivors and carers is through calls to the helpline. Staff on the helpline produce regular summaries of the questions and topics of conversation from callers. The helpline staff also moderate the Talk Stroke online forum and report on trends and concerns expressed there.

Survivors and carers are invited to formally contribute to funding decisions through the Service User Reader Panel (SURP), a group of people affected by stroke who are asked to input on all research proposals. They are sent plain English summaries of research proposals several times a year and asked to score and comment on them. These comments and scores are taken into account by the Research Awards Adjudication Panels in their decisions as to what to fund, but are not binding.

The association runs many workshops and regular surveys to identify unmet needs. For those who want to participate in trials more directly, researchers are allowed to recruit for subjects for clinical trials on the Talk Stroke Forum, and survivors and carers are directed towards the UK's clinical trials gateway.

Stroke Association engaged with the James Lind Alliance in a Priority Setting Partnership to identify areas of research which had been neglected. The long, structured process of engagements with 'key researchers in stroke research, research funders, stroke survivors and carers.' The partnership revealed much higher prevalence and levels of concern around the psychological consequences of stroke than the association had been aware of. This finding informed not only research direction but the development of projects including My Stroke Guide.

Lupus UK

Registered charity	2011
Paid Staff	6
Volunteers	300
Income 2013/2014	£940,315
Charitable expenditure 2013/2014	£891,900⁶⁹

Lupus UK has 6,000 members and provides support to local groups of volunteers who organise meetings for Lupus sufferers. The organisation has a website which presents some information on the condition as well as the links to the local groups. It organises regular awareness and fundraising campaigns.

Maria Elena Angel an anthropologist at UCL Department of Anthropology collaborated with the Collective Intelligence team at Nesta between January and May 2015 to produce a short ethnography of the Lupus support groups. Her work focused on two Lupus sufferers' groups in London. The object of her investigation was to understand the circulation of information within the groups and the role of digital tools for the circulation of ideas and experiences. Maria Angel attended the regular group sessions and also met and interviewed some of the participants individually.

Her research provided a rich and complex set of insights in patients' use of technology to support their daily life, increase their understanding of their condition and collaborate with others in constructing meanings. It revealed the extent of depth of the biomedical and experiential knowledge that patients share. The group meetings proved to be not only social environments for exceptional mutual support, but also loci of clinical discussions and knowledge exchange.

The monthly meetings bring together 20 to 30 sufferers, mostly women (who represent 90 per cent of Lupus sufferers) around an organiser who is also a patient. Most participants have been living with the condition for many years and are extremely knowledgeable about treatments and symptoms. The meetings which last a few hours, are a unique opportunity for exchange, friendship and discussion. These face-to-face encounters are continued online in Facebook groups, Whatsapp conversations, forums, phone calls and occasional social outings.

Holly uses the support group's Facebook account to read about discussions she may have missed, communicate with other members and keep up to date with the group's events and activities. She participates in the group's and other forums. She says that forums provide a safe environment to share experiences and to find information about Lupus and associated illnesses – including osteoporosis and Raynaud's syndrome (she has both). People describe their symptoms; share their experiences and how they manage their illness to lead a normal life. Others include a pregnancy forum, where users share their experience and advice. She says that doctors get 'a bit scared' when a Lupus sufferer wants to have a baby because the medication can put the pregnancy at risk, but the forum can provide advice on medication, diet and lifestyle as well as examples of successful pregnancies.

Ethnography of Lupus support groups Nesta 2015

The internet also provides sources of clinical information, experiential narratives from all over the world and a wide range of ideas and sources of inspiration and reflection. Often these themes are brought to the group meetings along with personal experiences of medication, care and suffering. The meetings provide an opportunity to assemble, validate, and make sense of the experiences and readings. By comparing notes sufferers attempt to generalise their findings and potentially validate their ideas. They do this mostly collectively and independently from the medical services they belong to. Their discussions and conclusions do not seem to move beyond the sphere of the patient group even though individually each patient is a part of a large web of relations. Maria Angel described some cross-fertilisation between the two groups she visited, essentially as a consequence of a certain overlap of a few participants.

Three things are striking in Angel's observations. Firstly, the groups are embedded in a network of institutions such as GP practices, hospitals, clinical units, social services, charity organisations, workplaces, schools, etc., but also informal networks of other patient groups and support groups. The group and patients are therefore nodes in a very complex web of relations and organisations. Secondly, all the participants are digitally active on social media, one-to-one communication channels, forums and in exploring the internet for information about Lupus. Finally, the knowledge produced in and by the group is not sedimented in any format that could be shared or simply analysed and reused. The other institutions involved in care, such as the clinical bodies they interact with are not exposed to this cumulative knowledge but simply to individual cases.

Currently Lupus UK does not offer a platform to capture and circulate the knowledge elaborated in the patient communities. The participants are aware of the value of the information they share and regret the fact that this body of expertise is not available to others (neither the clinicians nor new patients). Although they are digitally literate and active, they do not have any tool beyond Facebook to organise their experiences. Individually, participants occasionally participate in online patient forums from other countries.

ENDNOTES

1. Kelsey, T. (2013) Personalised Care Plans Will Give Patients Control of Their Own Health.' NHS England. Accessed March 25. See: <http://www.england.nhs.uk/2013/09/25/tim-kelsey-2/>
2. Ferguson, T. (2007) 'E-Patients: How They Can Help Us Heal Healthcare.'
3. Bastian, H., Glasziou, P. and Chalmers, I. (2010) Seventy-Five Trials and Eleven Systematic Reviews a Day: How Will We Ever Keep Up? 'PLOS Medicine.' 7 (9): e1000326.
4. Mehra, S., Leffler, D.A., Pallav, K., Tariq, S., Shah, S., Green, P.H., Hansen, J., Dennis, M. and Kelly, C.P. (2011) Socioeconomic Status Influences Celiac Disease Diagnosis. 'Gastroenterology.' 140 (5). Elsevier: S-438.
See: <http://jamia.oxfordjournals.org/content/early/2015/04/21/jamia.ocv025>
6. Epstein, S. (1995) The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials. 'Science, Technology & Human Values.' 20 (4): 408-37.
7. Rabeharisoa, V. (2008) Experience, Knowledge and Empowerment: The Increasing Role of Patient Organizations in Staging, Weighting and Circulating Experience and Knowledge. In Akrich, M., Nunes, J. and Paterson, F. (Eds.) 'The Dynamics of Patient Organizations in Europe.' Paris: Presses des Mines.
8. Ferguson, T. (2007) 'E-Patients: How They Can Help Us Heal Healthcare.'
9. Hu, F. Z., Preston, R.A., Post, J.C., White, G.J., Kikuchi, L.W., Wang, S., Leal, S.M. et al., (2000) Mapping of a Gene for Severe Pediatric Gastroesophageal Reflux to Chromosome 13q14. 'The Journal of the American Medical Association.' 284 (3), 325-34.
10. Terry, S. F., Terry, P.F., Rauen, K.A., Uitto, J. and Bercovitch, L.G. (2007) Advocacy Groups as Research Organizations: The PXE International Example. 'Nature Reviews. Genetics.' 8 (2): 157-64.
11. Kelty, C. and Panofsky, A. (2014) Disentangling Public Participation in Science and Biomedicine. 'Genome Medicine.' 6 (1): 8.
12. AMRC (2014) 'Charity Funded Research.' London: AMRC.
13. Fox, S. and Duggan, M. (2013) 'Health Online 2013.' Washington DC: Pew Research Center's Internet and American Life Project.
14. Roberts, C. (2009) 'Health Activism in Europe Today: Conference Programme and Preliminary Findings.' European Patient Organisations in the Knowledge Society.
15. Terry, S. F., Terry, P.F., Rauen, K.A., Uitto, J. and Bercovitch, L.G. (2007) Advocacy Groups as Research Organizations: The PXE International Example. 'Nature Reviews. Genetics.' 8 (2): 157-64.
16. IAPO Membership Criteria: Full Membership. n.d. IAPO.
17. IAPO Membership Criteria: Associate Membership. n.d. IAPO.
18. Despite their historical names, Alzheimer's Society and Alzheimer's Research UK now both support those affected by all forms of 'dementia' rather than specifically Alzheimer's.
19. Ramon, L.F., Leal, J. and Gray, A. (2015) UK Research Spend in 2008 and 2012: Comparing Stroke, Cancer, Coronary Heart Disease and Dementia. 'BMJ Open.' 5 (4): e006648.
20. Novas, C. (2009) Orphan Drugs, Patient Activism and Contemporary Healthcare. 'Quaderni.' No. 68 (January): 13-23.
21. Pryde, D. C., Palmer, M., Fox, D., Kent, A., Kimura, A., Boyd, R., Russell, A., et al., (2014) 'Orphan Drugs and Rare Diseases.' RSC Drug Discovery Series No.38. London: Royal Society of Chemistry. p122.
22. Landy, D. C., Brinich, M.A., Colten, M.E., Horn, E.J., Terry, S.F. and Sharp, R.R. (2012) How Disease Advocacy Organizations Participate in Clinical Research: A Survey of Genetic Organizations. 'Genetics in Medicine: Official Journal of the American College of Medical Genetics.' 14 (2): 223-28.
23. AMRC (2014) 'Charity-Funded Research.' AMRC.
24. Cody, J.D., Semrud-Clikeman, M., Hardies, L.J., Lancaster, J., Ghidoni, P.D., Schaub, R.L., Thompson, N.M., et al., (2005) Growth Hormone Benefits Children with 18q Deletions. 'American Journal of Medical Genetics.' 137A (1). Wiley Subscription Services, Inc., A Wiley Company: 9-15.
25. Chromosome (2015) '18q- Families: Jannine De Mars Cody.' Accessed April 16.
26. Landy, D.C., Brinich, M.A., Colten, M.E., Horn, E.J., Terry, S.T. and Sharp, R.R. (2012) How Disease Advocacy Organizations Participate in Clinical Research: A Survey of Genetic Organizations. 'Genetics in Medicine: Official Journal of the American College of Medical Genetics.' 14 (2): 223-28.
27. Kaye, J., Curren, L., Anderson, N., Edwards, K., Fullerton, S.M., Kanellopoulou, N., Lund, D. et al., (2012) From Patients to Partners: Participant-Centric Initiatives in Biomedical Research. 'Nature Reviews. Genetics.' 13 (5): 371-76.
28. Connect Befriending Service for People with Stroke and Aphasia in Gloucestershire. n.d. Connect.
29. Stroke News (2014) 'Two of Us.' November.
30. Burt, J. (2015) Social Workers. 'SWAN UK.' 19 February. See: <http://undiagnosed.org.uk/archives/6772>
31. Patient Innovation (2015) How It Works. Accessed June 29. See: <https://patient-innovation.com/tour>
32. Mazanderani, F., O'Neill, B. and Powell, J. (2013) "People Power" or "Pester Power"? YouTube as a Forum for the Generation of Evidence and Patient Advocacy. 'Patient Education and Counselling.' 93 (3): 420-25.
33. See Limb, L., Nutt, S. and Sen, A. (2010) 'Experiences of Rare Diseases: An Insight from Patients and Families.' London: RDUK.
34. Cukier, K. and Mayer-Schonberger, V. (2013) 'Big Data: A Revolution That Will Transform How We Live, Work and Think.' Houghton Mifflin Harcourt.
35. Armstrong, D. (1995) The Rise of Surveillance Medicine. 'Sociology of Health & Illness.' 17 (3). Blackwell Publishing Ltd. 393-404.
36. See account of Portia Iversen's work founding the Autism Genetic Resource Exchange (AGRE) in Ferguson, T. (2007) 'E-Patients: How They Can Help Us Heal Healthcare.'
37. Kaye, J., Curren, L., Anderson, N., Edwards, K., Fullerton, S.M., Kanellopoulou, N., Lund, D., et al., (2012) From Patients to Partners: Participant-Centric Initiatives in Biomedical Research. 'Nature Reviews. Genetics.' 13 (5): 371-76.
38. Clarke, A. E., Shim, J. K., Mamo, L., Fosket, J. R. and Fishman, R. (2013) Biomedicalization : Technoscientific Transformations Of Health, Illness, and U.S. Biomedicine. 'American Sociological Association.' 68(2), 161-194.
39. See account of Edwin Murphy in Ferguson, T. (2007) 'E-Patients: How They Can Help Us Heal Healthcare.'
40. Deep, K. S., Griffith, C.H. and Wilson, J.F. (2008) Communication and Decision Making about Life-Sustaining Treatment: Examining the Experiences of Resident Physicians and Seriously-Ill Hospitalized Patients. 'Journal of General Internal Medicine.' 23 (11): 1877-82.

41. McGuire, A. L., McCullough, L.B., Weller, S.C. and Whitney, S.N. (2005) Missed Expectations? Physicians' Views of Patients' Participation in Medical Decision-Making. *Medical Care.* 43 (5): 466-70.
42. Ford, S., Schofield, T. and Hope, A. (2006) Observing Decision-Making in the General Practice Consultation: Who Makes Which Decisions? *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy.* 9 (2): 130-37.
43. Upton, J., Fletcher, M., Madoc-Sutton, H., Sheikh, A., Caress, A.L. and Walker, S. (2011) Shared Decision Making or Paternalism in Nursing Consultations? A Qualitative Study of Primary Care Asthma Nurses' Views on Sharing Decisions with Patients Regarding Inhaler Device Selection. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy.* 14 (4): 374-82.
44. Kelsey, T. (2015) 'NHS England: Personalised Care Plans Will Give Patients Control of Their Own Health.' NHS England. Accessed March 25. See: <http://www.england.nhs.uk/2013/09/25/tim-kelsey-2/>
45. Kaffash, J. (2013) GPs 'More Likely to Be Sued than Ever before' as Claims Rise by 40% in a Year. 6 March. See: <http://www.pulsetoday.co.uk/your-practice/practice-topics/legal/gps-more-likely-to-be-sued-than-ever-before-as-claims-rise-by-40-in-a-year/20002162.article>.
46. Bourne, T., Wynants, L., Peters, M., Van Audenhove, C., Timmerman, D., Van Calster, B. and Jalmbrecht, M. (2015) The Impact of Complaints Procedures on the Welfare, Health and Clinical Practice of 7,926 Doctors in the UK: A Cross-Sectional Survey. *BMJ Open.* 5 (1): e006687.
47. Dumit, J. (2006) Illnesses You Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses. *Social Science & Medicine.* 62 (3): 577-90.
48. Akrich, M. (2010) From Communities of Practice to Epistemic Communities: Health Mobilizations on the Internet. *Sociological Research Online.* 15 (2). doi:10.5153/sro.2152.
49. NHS England (2015) The Information Standard: What Does Information Standard Certification Mean? Accessed 24 June. See: <http://www.england.nhs.uk/tis/about/description/>.
50. Swan, M. (2009) Emerging Patient-Driven Health Care Models: An Examination of Health Social Networks, Consumer Personalized Medicine and Quantified Self-Tracking. *International Journal of Environmental Research and Public Health.* 6 (2): 492-525.
51. Wyatt, S., Harris, A., Adams, S. and Kelly, S. E. (2013) Illness Online: Self-reported Data and Questions of Trust in Medical and Social Research. *Theory, Culture & Society.* 30(4): 131-150.
52. PatientsLikeMe Help Center (2015) What Is PatientsLikeMe? Accessed June 17. See: <https://support.patientslikeme.com/hc/en-us/articles/201186434-What-is-PatientsLikeMe->.
53. Tempini, N. (2015) Governing PatientsLikeMe: Information Production and Research Through an Open, Distributed, and Data-Based Social Media Network. *The Information Society.* 31(2): 193-211.
54. Swan, M. (2012a) Sensor Mania! The Internet of Things, Wearable Computing, Objective Metrics, and the Quantified Self 2.0. *Journal of Sensor and Actuator Networks.* 1(3): 217-253.
55. Since November 2013, the US FDA prohibited 23andMe from communicating of health related information- a ban that was lifted for the specific case of Bloom Syndrome in February 2015. 23andMe can still provide health information outside of the US and markets such services in other territories, including the UK.
56. Kaye, J., Curren, L., Anderson, N., Edwards, K., Fullerton, S. M., et al., (2012) From patients to partners: participant-centric initiatives in biomedical research. *Nature Reviews Genetics.* 13(5): 371-376.
57. Dolgin, E. (2010) Personalized investigation. *Nature Medicine.* 16(9): 953-955.
58. uMotif: uMotif Overview Video. See: <https://www.umotif.com/>
59. SBRI Healthcare (2015) uMotif Digital Health. Accessed 16 June. See: <http://www.sbrihealthcare.co.uk/case-studies/umotif-digital-health/>
60. Crohnology . Accessed 16 June 2015. See: <https://crohnology.com/>
61. RareConnect (2015) Alkaptonuria (AKU) Information and Resources, Frequently Asked Questions. - Accessed 6 April. See: <https://www.rareconnect.org/en/community/alkaptonuria-aku/learn/faq>
62. Overview | Healthtalk.org. (2015) Accessed 16 June. See: <http://www.healthtalk.org/about/overview>
63. Mathews, D. J. H. and Jamal, L. (2014) Revisiting Respect for Persons in Genomic Research. *Genes.* 5(1): 1-12.
64. Coombe, R. (1998) *The Cultural Life of Intellectual Properties: Authorship, Appropriation and the Law.* Durham NC: Duke University Press. Reprinted in 2008.
65. Cohen, J. (2012) *Configuring the Networked Self: Law, Code, and the Play of Everyday Practice.* New Haven CT: Yale University Press.
66. All Statistics: The Charity Commission for England and Wales (2015) 'AKU Society.' The Charity Commission for England and Wales. Accessed 26 June See: <http://apps.charitycommission.gov.uk/Showcharity/RegisterOfCharities/CharityWithoutPartB.aspx?RegisteredCharityNumber=1101052&SubsidiaryNumber=0>
67. All statistics Eczema Outreach Scotland 2015, Scottish Charity Register. Accessed 1 July. See: <http://www.oscr.org.uk/search-oscr/charity-details?number=SCO42392#results>.
68. All Statistics: The Charity Commission for England and Wales (2015) Stroke Association. The Charity Commission for England and Wales. Accessed 26 June. See: <http://apps.charitycommission.gov.uk/Showcharity/RegisterOfCharities/CharityWithPartB.aspx?RegisteredCharityNumber=211015&SubsidiaryNumber=0>
69. The Charity Commission for England and Wales (2015) Lupus UK. The Charity Commission for England and Wales. Accessed 26 June. See: <http://apps.charitycommission.gov.uk/Showcharity/RegisterOfCharities/CharityWithPartB.aspx?RegisteredCharityNumber=1051610&SubsidiaryNumber=0>

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