

# Technology and the Politics of Mobility: Evidence Generation in Accessible Transport Activism

Sunil Rodger<sup>1,2</sup>, John Vines<sup>1</sup> and Janice McLaughlin<sup>2</sup>

<sup>1</sup> Open Lab, Newcastle University, UK

<sup>2</sup> School of Geography, Politics and Sociology  
Newcastle University, UK

{s.d.rodger; john.vines; janice.mclaughlin}@ncl.ac.uk

## ABSTRACT

Digital technologies offer the possibility of community empowerment via the reconfiguration of public services. This potential relies on actively involved citizens engaging with decision makers to pursue civic goals. In this paper we study one such group of involved citizens, examining the evidencing practices of a rare disease charity campaigning for accessible public transport. Through fieldwork and interviews, we highlight the ways in which staff and volunteers assembled and presented different forms of evidence, in doing so reframing what is conceived as ‘valid knowledge’. We note the challenges this group faced in capturing experiential knowledge around the accessibility barriers of public transport, and the trade-offs that are made when presenting evidence to policy and decision makers. We offer a number of design considerations for future HCI research, focusing on how digital technology might be configured more appropriately to support campaigning around the politics of mobility.

## Author Keywords

Accessible transport; disability; activism; evidence; participation.

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous; J.3. Health; J.4. Sociology.

## INTRODUCTION

Digital technologies offer the possibility for the relationship between citizen groups and providers of public services to be reconfigured [49]. However, this relies upon active engagement of citizens with political and bureaucratic decision makers in pursuit of civic goals. In recent years, the HCI community has begun to examine the ways in which technology supports such engagements, for example through the use of social media platforms to support discourse around local planning [14], the design of lightweight systems for community consultation by civic society groups [60], and the use of sensors to collect

evidence around transportation infrastructure [38]. These examples highlight diverse uses of technology to collect and collate different forms of evidence (from sensor data to personal experiences and memories) used to inform, or sometimes contend, political decision making processes.

Despite growing attention being paid to new forms of civic action facilitated by technology, HCI research has rarely dealt with the issues of how evidence is generated by activist groups and the ways in which this is constructed, framed and portrayed to institutional authority. In this paper, we examine how a civic society group engages in a range of complex processes to collate, articulate, and represent evidence around matters of concern to decision makers. We report on our fieldwork with Muscular Dystrophy UK (MDUK), a charity that advocates and campaigns on behalf of people with rare to very rare muscle wasting conditions. During the period of our fieldwork, MDUK engaged in evidence-based activism [48], generating evidence around the accessibility of public transport for those with physical disabilities such as wheelchair users. This provided us with an opportunity to observe how a charity undertakes evidence collection and presentation, and to identify the new opportunities for design that these present.

We report on fieldwork conducted between June and August 2015. During this period, we: conducted a series of multi-day observational visits to MDUK offices; shadowed four wheelchair-using volunteers and staff members on evidence-collecting journeys around London; accompanied charity staff and volunteers on a visit to the UK Parliament to meet parliamentarians; and interviewed nine staff and volunteers involved in the collection and reporting of evidence. In studying this context, we build on prior work in the literature of disability and health activism on how patients’ groups seek to reframe what is perceived to be ‘valid knowledge’ through practices of evidence-based activism. In our findings, we offer two contributions to HCI discourse. First, we observe that not only is ‘evidence’ a complex and mutable resource for policymakers [38], but that it is collected and employed in many ways by campaigners for accessible transport in order to make a particular case to civic decision makers. Its value is not necessarily as an intrinsic form of authority, but in its ability to facilitate conversations and problematize existing understandings around an issue of concern. Second, we offer a number of design considerations for supporting

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future activist practices around public transport accessibility and rendering inaccessibility visible.

## BACKGROUND

### Technology, civic activism and public transportation

Prior work in HCI has suggested a variety of ways in which digital technologies may support different forms of civic activism around particular causes. It has been argued that by adopting a ‘public orientation’, HCI can expose and articulate matters of shared concern around experiences important to particular communities [18]. Different forms of engagement, including ‘illegitimate’ civic participation that takes place outside of traditional channels, can be supported by digital technologies [4]. However, social media may also enable novel forms of public lobbying of elected representatives, suggesting the power of technologies to reframe existing ‘legitimate’ channels of influence [32] as well as fashion new ones.

It has also been noted how technology can potentially disrupt how geographic place structures social relationships [8]. Conversations around local urban environments are embodied and political in nature [15]. Recent work has also elucidated the close relationship between people, places, and data, as well as the importance of considering how different forms of data may be captured, visualised and analysed by communities [56]. Others have directly addressed how digital technologies might be used to collect data to support local civic activism. Prominent examples include situated voting (e.g. [35, 57]), where lower barriers to entry may promote communities having a say in local matters of concern [57, 60]. Technology has also been explicitly designed to support activist groups and campaigns in data collection and generation. In the context of environmental activism, sensing technologies have been deployed on local civic authority vehicles [3] and used for participatory ‘citizen sensing’ [21, 37, 61]. The ways in which lightweight tools can be developed for and used by activist groups for situated public consultation on proposed planning developments have also been studied [60]. Mapping technologies have been combined with community-based evidence collection to support new forms of advocacy for breast-feeding mothers with geographically situated data [6]. Meanwhile, in city-level transport planning, crowdsourced data has been found to play authoritative, evidential and ambivalent roles, and is presumed to be objective despite its use as a mutable resource by stakeholders [38].

In the context of mobility and public transportation, mobile platforms have been used to examine accessibility through active and passive citizen sensing and crowdsourcing. *IBM Sidewalks* [54] enabled members of the public to report accessibility barriers to city officials, while [12] explored the potential use of smartphone sensors to passively collect and report accessibility while on the move. However, these studies focused primarily on assisting local government officials rather than empowering citizens, and gathered a

relatively narrow range of user responses and photographic or sensor data. Yet increasingly sophisticated and widespread use of mobile technology has also led to user-generated content being used for civic transport activism. A notable example is that of cyclists recording dangerous behaviour by other road users [2, 7]. Peer-surveillance or ‘sousveillance’ [41], particularly in the form of a ‘participatory panopticon’ of user-generated mobile content [13, 36], has been hypothesised as a way of challenging the asymmetry of civic surveillance [27]. In one study, the majority of live-streamed video content of a political or activist nature was ‘bottom-up’ sousveillance [19]. However, questions of trust and the motivation of proactive contributors of user-generated citizen journalism remain [28], suggesting that using such content to evidence particular civic claims may be problematic or contested.

### Knowledge and disability activism

There is a large literature examining issues of knowledge and evidence in the context of disability activism. Historically, disability has been associated with the medical and clinical constructs of a condition [31]. Although such knowledge has often been privileged over individuals’ views, opinions and experiences, recent decades have seen patients’ organisations redefine what is considered credible or valid knowledge, particularly for rare diseases [5]. Work in medical sociology, building on understandings of AIDS activist practices [22], has developed the concept of ‘evidence-based activism’ [48]. By collecting and articulating particular forms of knowledge, groups engage in the active epistemic reframing of issues of concern, and transform their relationship with authorities such as medical professionals and governments. This reframing particularly emphasizes experiential knowledge as a valid counterpart to credentialed knowledge, and is used by activist groups to reform their relationships with decision makers as members of expert networks. Evidence-based activism has served as an analytical lens in several areas including rare diseases [49], dementia care [48], and childbirth [1]. The latter, while not a medical condition *per se*, suggests that evidence-based activism is a useful tool in understanding how activists in medical-related fields challenge dominant discourses of knowledge and campaign for change.

In parallel to, though distinct from, this broadened understanding within the medical field of what constitutes ‘valid knowledge’, an activist-driven reframing of a hitherto ‘medical’ issue occurred with respect to disabilities. In the UK, the shift towards a ‘social model’ of disability stemmed from the 1976 Union of the Physically Impaired Against Segregation’s declaration that disability was the result of social oppression as opposed to physical impairment [58]. Disabled activists’ movements focused their attention on the institutions and environments that were seen to be creating disability [53]. Public transport is a spatial manifestation of unequal social relationships, with disabled people often denied the freedom to travel where and when they like [34]. As such, transport has been a

common focus of disability activists, including the Campaign for Accessible Transport that undertook direct collective action in the 1990s. Accessible transport is an area of particular importance as it is fundamental to many other aspects of full societal participation, including education, employment, and social activities. Furthermore, it has been noted that disabled people experience negative attitudes from staff or passers-by on public transport, highlighting how attitudes and social interactions influence ‘accessibility’ as much as physical barriers. Despite reported improvements in recent years [50], in 2013 the Transport Select Committee found disabled people’s access to transport in the UK was still “unacceptably poor” [33].

### **Technology and rare diseases**

A further relevant area of work is that of the role played by technology in supporting and influencing the lives of people living with rare and very rare conditions. The primary focus of this work has been on the design of assistive technologies for functional ‘improvement’, focusing on how technological adaptations can help to enable activities of daily living. In such research, the (potential) rarity of the disease itself is merely incidental. The focus is instead on how a wide range of technologies such as stylus-based text entry [62], gaze detection to support interaction with devices [29, 30], smart wheelchairs [59] and wheelchair-specific adaptations [12] might have utility for people with physical [55] or cognitive disabilities [16]. In many cases, the emphasis is on individual rehabilitation and participation (e.g. [25, 46]). Prior work specific to neuromuscular diseases includes software and adaptations to operate a PC [24], while wheelchairs as specific pieces of assistive technology have been the subject of advice aimed at patients and families produced by MDUK itself [45].

Technology has also been shown to be valuable for people with rare diseases as a means to facilitate relationships with others in similar situations. This can be observed in online communities such as SMA-space and PatientsLikeMe [47] where knowledge, expertise and information about the lived experience of conditions is shared. However, such platforms – particularly those supporting all rare diseases, rather than condition-specific sites – also reveal the challenges associated with bringing together heterogeneous individuals and groups with their own specific interests and priorities. Tensions across rare disease communities have previously been noted, with some groups reluctant to join umbrella organisations [52].

Most recently, MacLoed *et al.* [40] have brought the needs of people with rare diseases to the specific attention of the HCI community. In particular, they note a lack of current understanding on how technology might support advocacy processes for individuals with rare diseases and the groups that represent them. While their work was targeted to the domain of health and care, we extend this through a specific examination of how a rare disease charity goes about representing people with muscle-wasting conditions and

generates evidence around their experiences. We do this with a view to better understand how technology might facilitate particular types of campaigning around rare diseases in the future.

### **OUR CONTEXT**

Our data was collected over a period of three months as part of ongoing research studying campaigning and advocacy work by Muscular Dystrophy UK (MDUK) and its Trailblazers network. MDUK is a national charity covering more than sixty progressive muscle-weakening conditions that, though individually rare, collectively affect around 70,000 people in the UK [44]. While heterogeneous, these conditions clinically manifest in a loss of strength, and many individuals (especially those with more severe conditions) use wheelchairs for mobility. Founded in 1959, MDUK brings together affected individuals and families with professionals and aims to pursue high quality research, secure rapid access to treatments and care, and provide services to support social inclusion and independent living [44]. The Trailblazers are MDUK’s nationwide network of young disabled people, whose stated aim is to campaign against social injustices and enable access to education, employment and services. During the period of our fieldwork, Trailblazers were revisiting the issue of accessible transport [39], the subject of a 2009 campaign. Two surveys, advertised via social media and the charity’s website, were used to gather data from disabled people on their experiences of using public transport: a general survey about their overall experiences [42], and a ‘mystery shopper’ survey in relation to a specific journey they had undertaken [43]. Guided by the data received during the three-month survey window, the charity plan to compile evidence into a report, highlighting the most pertinent issues, to be launched at parliament and in the media.

Working with MDUK and Trailblazers during this period was interesting for a number of reasons. First, rare disease activism offers an engaging context in which to study the role of technology in reconfiguring relationships between a group of citizens and public service providers. The relatively small number of people living with rare diseases not only results in difficulties accessing appropriate medical care and in drug development [23], but also poses challenges for activists campaigning on social issues. Geographical dispersion and the heterogeneous nature of conditions mitigate against any one condition having sufficient weight of numbers to bring about change alone, and has led to rare disease organisations working together for increased impact [52]. In the case of accessible transport, this is apparent through MDUK’s collaboration with other groups and charities that share their agenda. Second, accessible transport is itself an important context given its centrality to full societal participation amongst those with disabilities. Their exclusion from everyday public life, due partly to inaccessible transport, has been noted in the disability activist literature. Yet the potential

role of technology in campaigning on this issue has yet to be investigated.

### Method

Fieldwork was undertaken during three separate visits by the lead author (totalling 8 full days) to MDUK between June and August 2015, comprising four broad activities. Initially (i) it included observation at the charity's offices and informal conversations with staff and Trailblazers. This gave us an understanding of the main issues involved in the public transport campaign, how the charity intended to undertake their campaigning work, and how the organisation was structured. Semi-structured interviews (ii) were conducted with nine staff members and volunteers from the organisation. These focused on understandings of evidence and its use in campaigning, the campaign around accessible transport, and the role(s) of technology in helping to evidence current or future campaigns. The third stage (iii) involved accompanying staff and volunteers to the Annual General Meeting of the All Party Parliamentary Group (APPG) for Young Disabled People in Westminster. An APPG is a cross-party group of MPs who share an interest in a particular issue and hold regular meetings on specific themes with invited stakeholders including campaigners, civil servants, and decision makers. This afforded an opportunity to observe the ways in which MDUK and the Trailblazers engaged in conversation and discussion of their campaign in what could be seen as a highly 'legitimate' space for civic action. The fieldwork and interviews at MDUK were supplemented by (iv) travelling on 7 separate journeys (totalling ~10 hours) with 4 wheelchair-using staff members and Trailblazers volunteers around London's public transport system. These journeys involved use of the Underground, Docklands Light Railway, buses, and local trains. Some journeys were incidental, accompanying a Trailblazer or staff member on their commute from MDUK offices to their 'home' station; others were undertaken explicitly for the purposes of data collection for the Trailblazers transport campaign. These journeys provided valuable first-hand observations of issues faced by wheelchair users on public transport, and how evidence was gathered and constructed around these issues.

### Analysis

All nine interviews were recorded, transcribed, and anonymised with staff members hereafter denoted by the prefix *SM* and Trailblazers with *TB*. Data also comprised the lead author's field notes, which documented observations and interactions made throughout the fieldwork, including the journeys on public transport. A smartphone was used to note points of interest during journeys, and for photographic and video documentation. Thematic analysis [9] was undertaken, chosen for its flexibility and ability to identify recurrent and meaningful patterns within heterogeneous data. To understand both explicit and underlying issues raised by participants, transcripts were coded by the lead author at the sentence level for semantic and latent meaning. Drawing upon and

integrating insights from observations, tentative themes were identified and clustered. These were reviewed by the other authors, who agreed upon the final themes presented.

### FINDINGS

Our analysis of the data resulted in four overarching themes, which are discussed in the following sections.

#### What is felt, articulated and assumed to be evidence

Although all participants had opinions on evidence, the term itself defied concise definition. It was often regarded as "*what people tell you [...] that you can reliably ascertain as truth*" (SM-1), or "*speak[ing] objectively about the facts*" (SM-6). At a superficial level, participants articulated 'evidence' as objective or factual information, conveying 'how a situation really is' as opposed to unsubstantiated hearsay. Although this implicitly suggests a single 'truth', participants also recognised that there may be competing, subjective perspectives on accessibility issues.

Unprompted, most participants distinguished between what they described as 'quantitative' and 'qualitative' evidence. The former was characterised as clinical and detached, the "*cold numbers which you need to show a trend*" (SM-5). Quantitative evidence possessed an intrinsic robustness, "*the concrete facts and stats to have it be accepted as... a valid issue*" (SM-5). Another staff member described the role of statistics in reports and press releases as highlighting the importance of an issue: "*getting people to understand 'ok, these are the big statistics, this is what kind of... gives us a bit of weight towards what we're doing'*" (SM-9).

Given these understandings of quantitative evidence and the perceived importance of statistics and demonstrating trends in their campaigning, staff aimed to maximise the number of responses to the surveys they were running. While acknowledging there was no defined threshold for a 'good' number of participants, one suggested that:

*"Obviously we'd want to get as many people as possible responding... I think if you're able to get... at least into sort of three figures, you're looking at a respectable number that... I think will be taken with... serious consideration by anybody"* (SM-4).

As this suggests, despite the perceived power of numbers, participants were unable to articulate how much evidence was sufficient, nor precisely why this was the case. Instead they relied on past experience of 'what worked' to help guide their campaigning activities. This implicit elevation of numbers reflects the 'politics of numbers' in rare diseases, a campaigning strategy challenged by a 'politics of singularisation' which argues against the subjugation of individual lived experiences by aggregate statistics [52].

In contrast to 'quantitative evidence', what participants described as 'qualitative evidence' was valued for the ways it brought particular issues to life. Typically, this evidence was individual testimonies: personal stories that conveyed lived experiences. These were seen to be especially

valuable in communicating with lay decision makers who, it was felt, otherwise struggled to empathise with the experiences and perspectives of disabled people:

*“[people] who don’t have a disability won’t necessarily understand what it’s like to live with it on a day-to-day basis... politicians say ‘ok this is an issue, we have to do something about it’ but then when they hear stories and are confronted by families... you get the emotional side of it” (SM-5).*

Although the emotional power of testimony was rooted in its ability to tell personal stories, not all testimonies were helpful for campaigning. Several staff mentioned that while anecdotes could illustrate an issue, photographs or videos strengthened such accounts as they moved away from the realm of the anecdote towards the verifiable:

*“Videos and photos of people... that [is] tangible evidence, rather than it just being people’s experiences, it’s kind of showing hard evidence with photography or video” (SM-9)*

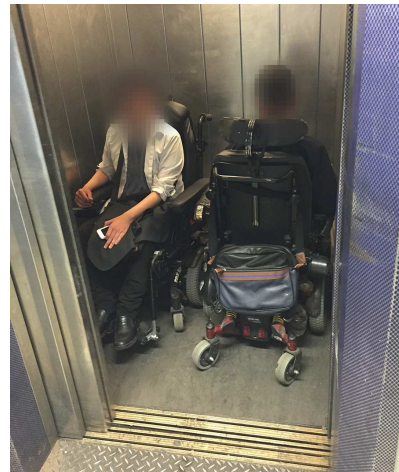
*“A video or a picture... that makes your case study, your qualitative data so much stronger... Having footage, having video, having images that people can look at, helps to give your qualitative data some strength” (SM-1)*

Visual imagery was clearly privileged as a form of documentation and communication compared to other forms of testimony. It was valued for its ability to demonstrate an injustice or problem to third parties such as decision makers. Visual imagery was also seen to be easily promoted and propagated via social media: *“it can be tweeted out”* and *“becomes not so much anecdotal but... on the record!”* (SM-3). Through such mediums specific issues could be brought not only ‘to life’ but also brought to a wider public audience.

Given the perceived strengths and weaknesses of different types of evidence, the charity integrated and presented a range of complementary forms of it in support of their aims. This was associated with an understanding that although experiential, case-study led reports and personal testimonies were important, there was a need to balance different forms of evidence in order to broaden from the individual to the collective experience.

### **Evidencing the experience of public transport**

Primary evidence collection during the Trailblazers’ public transport campaign hinged upon two online surveys: a general one on experiences of travelling on public transport; and a second, targeted one asking about the detailed experience of a specific journey. The former captured broad experiences across a range of different transportation types (buses, trains, taxis and underground services). It asked closed and open-ended questions on journey planning, attitudes of staff and passengers, accessibility features of modes of transport, and the personal impact that being unable to travel had on respondents’ lives. The second



**Figure 1: Two volunteers using a goods lift at a major London railway station in preference to the passenger lift.**

survey asked people to articulate in detail a specific journey they had undertaken, reporting when, where and how they experienced this journey, and asking for examples of good and bad practice. The surveys aimed to capture quantitative and qualitative forms of evidence, which would be collated and used to inform the next stages of campaigning.

During the fieldwork, it became evident that by their nature these surveys had limitations in capturing the full experience of public transport. This was highlighted when accompanying Trailblazers on journeys to test out specific accessibility services provided by Transport for London (TfL), the local government organisation responsible for most aspects of London’s transport network. They now offer a ‘turn up and go’ service that aims to provide disabled people with the same flexible, spontaneous access to public transport as non-disabled people. However, we observed a variety of ways in which journeys were still not equal. Some of these were due to ongoing accessibility problems with equipment and vehicles. For example, we observed occasions where participants travelling in pairs had to split up, with the second individual waiting for the next bus, due to each bus only having space to accommodate one wheelchair or pushchair. Elsewhere, participants used a goods lift rather than the designated passenger lift at a major London terminus (Figure 1). The latter deposited users into a busy flow of pedestrian traffic, while the former not only had more space in which to manoeuvre powered wheelchairs, but also took participants directly past the platform assistance office that they would need to go to anyhow.

We also observed a range of social and attitudinal challenges participants faced when conducting their journeys, particularly when travelling by bus. For health and safety reasons, the deployment of bus ramps is accompanied by a loud siren that draws embarrassing and unwanted attention to the presence of a disabled passenger, which could be a distressing experience:

*“waiting for the ramp to come out from the bus and it not working properly and it all beeping and... people staring at you” (SM-2)*

We observed this issue on several occasions during our fieldwork. In another instance a driver sternly called down the bus to a participant to reposition their wheelchair for safety reasons, a physical impossibility while the bus was moving. One driver also ignored the wheelchair user and instead interacted with their personal assistant, in a manner perceived to be highly demeaning by both our participant and by fellow passengers who remonstrated with the driver.

Aside from these specific instances, we also noted that participants face myriad everyday challenges accessing public transport. Journeys took considerably longer and were more inconvenient than those of non-disabled people: wheelchair users navigated greater distances and multiple lifts to access underground station platforms; there was a significant amount of waiting around, either for staff and ramps or for vehicles with sufficient space to arrive; they had to position themselves in specific locations to get on and off buses and trains, sometimes in uncovered areas; and there was a lack of flexible and convenient access to amenities that many take for granted such as cafés or toilets. Participants even reported several occasions where pre-arranged ramps had not been provided at their desired disembarkation point, leaving wheelchair users trapped on the train and headed to an unintended destination.

All of these experiences paint a picture of a diverse range of situations that were often hard, or even impossible, to capture, document and express via text-based surveys. In part this was due to their retrospective nature, where feedback was essentially a reflective summary of the journey undertaken. The question of how best to ‘capture’ or ‘document’ these issues from a broad range of respondents was thus understood as problematic. Given the aforementioned perceived benefits of visual media as a form of testimonial evidence, it is perhaps unsurprising that many participants suggested film or photography as alternative means of capturing experiences from journeys. At the same time, concerns were raised around personal security and safety. There were fears that such capturing might be *“seen as an aggressive thing to do”* and it was suggested that a less obtrusive method of filming *“would probably be safer”* (SM-2). In addition, due to the physical decline associated with progressive muscle-weakening conditions, quickly producing a camera or phone to capture a situation was recognised as difficult if not impossible.

The issues articulated in this theme highlight the diversity of challenges mitigating against evidencing the experience of public transport. Although there is a desire to generate what is perceived to be authentic evidence around issues of accessible transport, the journeys and processes utilised by the charity for capturing them are acknowledged as possessing significant limitations.

### **Assembling, presenting and articulating evidence**

Our third theme relates to the practices adopted and challenges faced by the charity in assembling different types of evidence to bring about change. Staff described campaigning as a *“constructive dialogue... actually saying ‘these are practical things that you can do’”* (SM-9). This implied close engagement with decision makers:

*“at the end of the day we want to... have as much sort of constructive and direct access with... those who are able to change things and make things better”* (SM-4)

The notion of direct access in this context incorporates several Parliamentary activities, including providing the secretariat for the All Party Parliamentary Groups (APPGs) for Young Disabled People and for Muscular Dystrophy. In fulfilling these roles, the charity is able to help set the agenda for the meetings based on issues raised by their constituents. It also affords individual campaigners the chance to attend an APPG and communicate their experiences in person. Such meetings are considered invaluable and effective in bringing stakeholders together and raising awareness:

*“compared to just receiving a letter on A4 paper... people at the top... are sometimes genuinely shocked... they may not necessarily consider disabled people on a daily basis”* (SM-9).

The charity considers public transport to be a particularly complex area in which to campaign, with this workload shared between several members of staff. This is partly due to the many actors involved in public transport issues, including local and national government bodies, organisations like TfL, and privatised transport operators. Faced with this complexity, the charity adopts a mixed strategy of insider lobbying complemented by public activism. As described by one staff member, *“part of our job is to sort of highlight things ... but on the other hand sometimes [a] softly-softly approach works better; of kind of going discreetly to that organisation”* (SM-2). The ability to pursue this approach, while retaining professional working relationships, was considered very important:

*“We operate on an insider lobbying basis, but if we get blocked we’re quite prepared to go on the outside track as well and bring media pressure to bear, and to go out in the public domain and argue. [W]e have this ability to sit down face to face and seek solutions and put pressure on, but we know, and it’s not [...] threatening... it’s just a fact, that in addition to that face to face contact, where we are putting an argument, putting facts across, and making a case, if need be we can put in media pressure... [and] the patient voice [to]... show the force of our case in those terms.”* (SM-3)

This reformist approach, working within networks of decision makers to apply pressure for change, is characteristic of evidence-based activism. However, it also relies on meeting the expectations of decision makers in



terms of evidence, and staff weighed up the respective merits of different forms of evidence when faced with this reality. In particular, they felt that in conversations with policymakers they had to make the economic case for investing in accessible public transport by factoring in the overall cost to society of not implementing changes:

*“if public transport say from my house to my local hospital was more accessible... then I could use public transport and the cost to the NHS [National Health Service] would fall”* (SM-1)

Putting a precise cost on these social benefits was acknowledged as exceedingly difficult if not impossible. Therefore, in some cases they appealed to ‘common sense’, such as with the continued deployment of portable ramps at Underground stations after the 2012 Olympics:

*“TfL initially said... ‘that was just for those weeks’... and [we] said ‘if you can do it at the busiest time ever, then there shouldn’t necessarily be a reason not to be able to do it now.’”* (SM-9)

Similar comments about accessibility as an issue that just ‘made sense’ were voiced by all the wheelchair users on the journeys they undertook, often when confronted by inaccessible equipment or technology such as badly located bus-stop poles (see Figure 2) or non-dropped kerbs.

Following up with decision makers was also regarded as important, with Parliamentary campaigning not an end in itself but a starting point for ongoing engagement:

*“we’d always try to be getting sort of meetings with... the Minister and his or her officials so that we’re taking the issue as high up... as we possibly can”* (SM-4)

This also suggests a broader question around the role of evidence in bringing about change. Although regarded as important for opening the door to conversations with decision makers, and valuable in persuading them of the extent and seriousness of a concern, there was also a recognition that evidence alone may be insufficient to bring about change. As one participant put it:

*“It might be less about... the evidence and more about the individuals who are involved in terms of pursuing... those people that we’ve met and badgering them and... keeping on them... to work with us to fix some of the problems we’ve identified... as opposed to ‘this type of evidence was better or stronger.’”* (SM-6)

While evidence is believed to be important, it thus works alongside the charity’s insider lobbying strategy. Should novel forms of evidence be employed by the charity for campaigning, this may suggest that they might best function as a way of enabling these conversations. As such, it also highlights the critical importance of the broader political context in which evidence operates.

### Scarcity of evidence

As with many other rare diseases, a significant challenge to any sort of campaigning is posed by the rarity of muscle



**Figure 2: A bus ramp obstructed by street furniture, which would not support the weight of a powered wheelchair. After able-bodied passengers disembarked, the bus moved forward and redeployed the ramp before our participant could get off.**

wasting conditions. One staff member noted that a problem for the charity in influencing a range of policies, unlike in campaigns associated with more common conditions, is that *“the evidence base is often weak”* (SM-3). Although this consequence of rarity is perhaps most clearly manifested in health issues, such as delayed diagnosis and lack of specialist care [23], it also has implications for the evidence base when campaigning around social issues. Several staff mentioned that Trailblazers’ specific focus on young people might further narrow the constituency of actors engaged in campaigning, and that this could, at least potentially, lead to difficulties when bringing their cause to decision makers:

*“[if someone said] ‘you only had a hundred young people take part in this survey so that’s not really a huge issue’... that’s one of the issues that we’ve had”* (SM-6).

In addition, the physical limitations caused by neuromuscular conditions can make it difficult to contribute to campaigning. Staff acknowledged that this could be particularly problematic for this population, for whom even taking the journey itself could be both physically and emotionally draining. Subsequently reliving this experience to provide rich and detailed feedback, even with the goal of improving the situation in the future, *“can seem like a massive task”*, particularly if they require the help of a carer to fill in a survey (SM-9). This reliance on others could also be disempowering when attempting to capture evidence ‘on the go’: one participant noted the necessity for their personal assistant to help them use their phone to document an issue, commenting that those with the condition will eventually *“reach a stage where they would be like ‘oh, we can’t do that [anymore]... it’s just another... thing to add to our list’ [of things we cannot do]”* (TB-7).

A further challenge around scarcity for this campaign was associated with the emotional legacy caused by bad experiences on public transport. While none of our participants described experiences that were so detrimental that they would no longer travel, one did relate that they generally avoided bus travel based on a prior incident. Throughout the course of our fieldwork, staff members and Trailblazers recounted stories of other people for whom a negative experience while travelling had resulted in a deeply adverse impact on their life. Although such stories would offer substantial testimonial evidence for the campaign, it was acknowledged that the emotional burden of such experiences means they rarely get shared:

*“A lot of people are quite private, especially after they've gone through a huge battle. They're not amazingly keen to have their names out there...and it's particularly difficult with the more useful case studies. So the more emotional the story is, the harder it is” (SM-5)*

The challenges posed by the scarcity of evidence, stemming from both the rarity of neuromuscular conditions and from the emotional and physical barriers to capturing experiences, highlight the difficulties faced by MDUK in collecting evidence for their campaigns. There is an inherent tension here between bridging the different forms of evidence that were perceived as valuable – that of numbers and of testimony – when numbers are hard to achieve and the most powerful testimonies may be from those who are least willing to speak. Perhaps because of this, it is not surprising that we observed the primary role of data and evidence to be helping to structure and facilitate conversations with policymakers, rather than to make authoritative claims on their own.

## **DISCUSSION**

Our findings highlight the ways in which staff and volunteers at a national neuromuscular charity understand the concept of evidence, and their practices in assembling evidence around a campaign for accessible public transport. They face complex challenges and responsibilities in ‘translating’ evidence for policymakers. While crucial to the campaigning work they undertake, evidence was an amorphous concept that was often difficult to define. The specificities of rare diseases meant that the pressure to play a ‘numbers game’ was at odds with the reality of the population on whose behalf they campaign. Similarly, although journeying offers a rich set of experiences that could be harnessed to report on and evidence of a range of accessibility issues, current practices of capture – and the challenges to participating in this activity in the first place – can impede this. In spite of this, staff assemble such evidence in ways that attract the attention of the decision makers with whom they engage, and are mindful of these stakeholders’ expectations or requirements.

The perceived value of experiential evidence, as highlighted by prior work on evidence-based activism [51], was clearly articulated by charity staff and volunteers. Although such

evidence is an emotional hook that attracts the attention and empathy of policymakers, it simultaneously serves to reframe issues: from transport policy or service delivery to the lived, human experience of the difficulties faced by disabled people around accessible transport. In doing so, the activities of the charity appear to continue the tradition of evidence-based work by neuromuscular patient organisations in the ‘problematization’ of particular issues of concern and in the accumulation of knowledge [10]. It also has much in common with the reformist-based approach to policy change of evidence-based activism [51].

Yet friction also emerged between different types of ‘evidence’ as they were conceptualised at the charity. In particular, staff expressed a need to balance narrative, experiential ‘qualitative’ evidence with ‘quantitative’ evidence in order to achieve their goals. The latter was perceived as necessary to justify the need for systemic change to policymakers, and was often framed in economic terms. This serves to emphasise how charities like MDUK have to work to fit the evidence they generate into a broader policy framework of what is considered ‘valid’ and actionable. In the cases we saw, issues were often expressed as a cost-benefit or affordability issue. With this often came a further level of framing and distilling of evidence to the audience being lobbied and the specific objectives that the charity seeks to achieve. As one participant explained:

*“we sometimes talk about policy-based evidence-making... we may have an objective we're keen to achieve... And we'll look for the published evidence that would make the case, and if there isn't any there, then we'll look to generate [evidence on that issue]” (SM-3)*

These factors in turn call into question the extent to which the charity is able to successfully reframe what constitutes ‘valid’ knowledge, following in the tradition of evidence-based activism. Indeed, MDUK may be constrained by existing understandings of what is considered ‘valid’ evidence by both policymakers and activists themselves. Our research also highlights that evidence, and the technologies used to capture and represent it, do not exist in a depoliticised vacuum. Rather they operate within a much broader context of personal and organisational relationships, policies, and understandings of the issues at stake. Previous work has emphasised that HCI must engage with the political and social contexts within which it operates [17, 20]. In doing so, it will be better placed to build tools that, in bridging the gap between awareness-raising activism and hierarchical governance structures, may bring about societal change [26]. HCI should therefore consider engagement in a range of diverse areas, including the processes of lobbying, whether different audiences for and potential beneficiaries of evidence might be identified, and how people might be supported with new ways to interpret and interrogate evidence itself.

These findings raise a number of implications for the ways we might envisage technologies being used in disability



activist practices and campaigns, as well as for activism and campaigning work more broadly. They open up opportunities to explore new tools for evidence collection that may empower people with muscle wasting conditions to capture more nuance, detail, and richness around their experiences. However, our findings also highlight potential barriers for the successful appropriation of new systems – both for those capturing and evidencing their experiences, and for those using these data to campaign and advocate for change. We discuss these issues in the following sections.

### **Designing for the politics of mobility**

In the following section we highlight the implications of our findings for how we as a research community might design for the politics of mobility.

#### *Tools for rendering the inaccessible visible*

It was clear from our findings that accessibility is a highly complex topic, and that inaccessibility can at times be challenging or even impossible to express. Through the course of our study we noted how participants experienced not just a range of physical accessibility barriers, but also social, organisational, and attitudinal issues that made transport inaccessible. Each raises different implications for the design of digital tools that might capture, represent, and render visible the inaccessible.

The emphasis on representing the experiential aspects of inaccessible transport suggests an assumption that issues of accessibility can be captured and conveyed to others via visual media such as photographs or videos. This may be true in certain circumstances. Like cycling activists [e.g. 2, 7] we could imagine near-futures where Trailblazers journeyed with GoPros or other video surveillance and life-logging equipment attached to their wheelchairs so as to capture instances of malfunctioning ramps or rude members of staff. Equipment could be further configured to only capture events prior to a specific button press, to alleviate re-watching extensive video footage or reviewing large numbers of images. Alternatively, we might provide a retrospective annotation tool to enable rapid editing and narration after a journey is completed. However, there are reasons to be cautious about the value of such approaches. There was a reticence amongst our participants to draw further attention to themselves – and being seen to engage in surveillance may increase fears of encountering duress. Furthermore, in light of our participants' experiences, it would be unfair to expect people to undertake laborious retrospective data editing.

An alternative approach might be to design hidden tools that offer alternative ways of capturing issues of access. GPS data enables the logging of 'dwell time' in locations, the routes people have to take, significant deviations to journeys that occur, and the length of travel time. Accelerometer and gyroscope data can capture the quality of the surfaces travelled upon, the amount of manoeuvring that takes place, and periods when people can't move [38]. Furthermore, simple physical buttons and switches attached

to wheelchairs might be used to discreetly report felt experiences of negativity and exclusion. Each of these raise new issues for how technically complex data might be presented to lay people and policymakers, as well as challenges for the interpretation of reported experiences. Yet they offer rich ground for rendering the inaccessible visible to audiences, without burdening wheelchair users with written reports or recounting through testimony.

#### *Facilitating evidence-based activist conversations*

During our fieldwork it was notable that specific forms of evidence were framed and represented in particular ways by the charity, often in order to facilitate conversations with policymakers around the issue of accessible transport. While we read of 'big data' and digital datasets as offering simple answers to complicated problems [56], evidence as it was constructed and communicated here was not an objective and unbiased representation of the world. Data, and the articulation and capturing of personal testimonies as evidence, did not itself offer an answer to the messy complexities of decision making.

Instead, evidence was collected, framed, talked around and positioned with a deep consideration of its intended audience. There is a need for evidence to *speak directly* to its intended audience in their own language, and fit within accepted parameters of validity, which in turn constrains the forms of evidence that are collected and represented. If evidence must conform to policymakers' existing conceptions of 'qualitative' (people's narratives) and 'quantitative' (economically justified), then campaigners may be unwilling to adopt some of the novel technologies above that might radically reimagine evidence. This implies that technology may serve only to perpetuate existing conceptions of evidence – for example by making it easier to create experiential videos that support particular narratives and facilitate existing conversations – rather than challenge current understandings and provoke new ideas of what evidence might look like. Yet we might also design ways for policymakers to understand the intrinsic value of hitherto marginalised forms of evidence. Rich multimedia reports might help campaigners to articulate links between the social and economic benefits of accessible transport, explicitly highlighting the interconnectedness between experiential and aggregate 'data' and 'evidence'. These may begin to address the challenge of going beyond evidence itself and bringing about political change.

#### *Triangulating experiential evidence*

The complexity of interactions during journeys on public transport was evident during our fieldwork. In addition to technological factors such as buses, trains and lifts, Trailblazers interacted with their personal assistants (where present), members of transport staff, and other passengers. Design that is mindful of these diverse actors, and their unique perspectives on issues of accessible transport, is important and may open up interesting possibilities for evidence and campaigning. We noted that it was often our third-person perspective as researchers that highlighted the

sheer lunacy of some issues of accessibility: for example, we observed interactions between the Trailblazers and failing technologies or third parties from a vantage point that afforded us a clear view of what was going wrong. At times like these, it may not be possible for an individual to articulate precisely what an issue is; at other times, a first-person perspective does little to communicate to others the scale of the issue at hand. A third person perspective allows others to ask ‘my experience is like this, why isn’t theirs?’. These ‘other’ perspectives are distinct from that of the Trailblazer, and although they should not be privileged over their lived experience, they may prove invaluable for ‘triangulating’ the complexities of different experiences around accessible transport.

Indeed, this may be essential for evidence that is used for structuring conversations with policymakers: one might imagine how third-party testimonies could strengthen the personal accounts of issues of transport inaccessibility. This could open up a design space for ways of facilitating collaboration between campaigners and other passengers or citizens as co-activists. One might imagine technologies such as social media enabling the participation of ‘third-person activists’: rather than creating evidencing tools for an individual, we might design tools to enable collaboration with co-travellers who could collect data or provide testimony on behalf of that individual. Such technologies, designed to enable activists to align their interests with other actors, might even be used to bridge different scales of geography and governance [20]. Alongside co-located ‘crowdsourcing’ as described above, social media could also be better harnessed to provide global perspectives and tools for best-practice sharing on local problems. In other words, it might provide a means for navigating the issues of dispersion and small numbers of concerned individuals by harnessing the will and experiences of people facing similar accessible transport issues across diverse geographic and cultural contexts. However, we acknowledge an inherent tension in designing such tools, as our data suggest that the ‘constructive’ feedback valued by decision makers was specific, geographically localised, and directly actionable.

#### *Adaptability and configurability*

Finally, our work emphasises the importance of designing technologies that are adaptable and configurable, which has several implications in the context of activism around accessible transport. Technologies in this space must address both the immediate priorities and capabilities of those undertaking evidence gathering and construction. For example, when discussing the value of video recording with Trailblazers as a way they might generate evidence, they suggested other uses including enabling them to take photos throughout their daily lives, and recording university lectures for later recall. This suggests we need to ensure that tools for evidence collection are also tools that fit within the aspirations and routines of individuals’ everyday lives. Tools used for activism might be the very same tools used when socialising, playing and learning.

Additionally, particularly apparent from working with MDUK was the diverse physical capabilities of those living with progressive, heterogeneous neuromuscular conditions. This emphasises the critical importance of flexible and sensitive design in both hardware and software, as noted in previous work on chair-mounted technologies [12]. Designing technologies for use by this population thus requires attending to the specificities of individual needs and preferences. Adaptability of tools is also important in progressive conditions where specific physical capabilities are lost. The forms of evidence that are most appropriate for any given cause, and that people are able and willing to collect given their own circumstances and individual preferences, will inevitably be heterogeneous. Some may be unable, for example, to supply video based data but might feel comfortable contributing GPS tracks or a testimony. We need to be able to appreciate many different forms of evidence: vocalised, implicitly collected, numeric and experiential, and think not only about the tools which could collect these, but also how they might work together in combination to support specific goals. Although this is challenging, we suggest that an incremental, user-led development of tools is likely to yield more productive results than a one-off engagement.

#### **CONCLUSION**

This paper investigated the ways in which staff and volunteers at a national rare disease charity conceive of evidence and assemble it in specific forms around the issue of accessible public transport. While conceptions of what evidence was and its value were diverse and disparate, there was a great emphasis on the significance of experiential knowledge and a realisation that evidence is consciously framed to speak to specific audiences. Our study raises a range of important considerations for how the HCI community and designers might conceptualise how new forms of evidence are generated through digital systems and tools. We have suggested a number of directions for future work to support the politics of mobility, appreciating the heterogeneity of motivations, skills and abilities of those who engage in such campaigns and the collaborative nature of this activity. Furthermore, we have signalled how while there is an ambition to undertake evidence-based activism, primarily there is a practical need to fit evidence to existing frameworks as understood by decision makers.

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