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Towards including end-users in the design of prosthetic hands: Ethical analysis of a survey of Australians with upper-limb difference

Advances in prosthetic design should benefit people with limb difference. But empirical evidence demonstrates a lack of uptake of prosthetics among those with limb difference, including of advanced designs. Non-use is often framed as a problem of prosthetic design or a user's response to prosthetics. Few studies investigate user experience and preferences, and those that do tend to address satisfaction or dissatisfaction with functional aspects of particular designs. This results in limited data to improve designs and, we argue, this is pragmatically and ethically problematic. This paper presents results of a survey we conducted with people with upper limb difference in Australia. The survey sought to further knowledge about preferences surrounding prosthetics and understanding of how preferences relate to user experience, perspective, and context. Survey responses demonstrated variety in the uptake, use and type of prosthetic – and that use of, preferences about, and impacts of prosthetics rely not just on design factors but on various contextual factors bearing on identity and social understandings of disability and prosthetic use. From these results, we argue that non-use of prosthetics could be usefully reframed as an issue of understanding how prosthetics can best support users' autonomy. This supports the claim that there is a need to incorporate user engagement into design processes for prosthetic limbs, though further work is needed on methods for doing so.

Keywords: prosthetics, end-user, ethics, disability, upper limb difference

Recent technological developments employed in the design of prosthetic limbs present new benefits and opportunities for people with limb difference. There are questions about how to best harness these benefits and opportunities. Assistive technology design can result in technologies that are not usable by or acceptable to end-users, raising questions about what erroneous assumptions about disability may be informing design. In the broader

disability literature, there is recognition of the need for designers to engage with end-users. However, little research has been done into prosthetic users' preferences, and what research exists tends to focus on problems experienced with current devices. The tendency is to frame non-use of prosthetics as a problem with device design or with how users respond to designs.

To contribute to the evidence-based on prosthetic users' preferences, our interdisciplinary research team at the Australian Research Council (ARC) Centre of Excellence in Electromaterials Science (ACES) undertook a survey of people with upper-limb difference in Australia.¹ We focussed on upper-limb difference because members of the research team are biomedical and mechatronic engineers involved in the design of a new prosthetic hand and engaging user preferences presented the opportunity to influence design in its early stages.² Further, people with upper limb difference have been underrepresented in surveys on prosthetic use in Australia, perhaps reflecting that the number of people with upper limb difference in Australia is significantly lower than lower limb difference (no precise data are available, but see Limbs4Life 2011, 7), and so have had fewer options for prostheses given little investment in research and development (O'Brien 2018, 5). The survey, developed in consultation with prosthetic user groups, sought information about preferences, needs, and factors affecting prosthetic choices and use to deepen understanding of how preferences relate to user experience, perspective, and context. Responses demonstrated variety in terms of uptake and use of prosthetic; and that uses of, desires for, and impacts of prosthetics rely on a range of contextual factors bearing on identity and social understandings of disability and prosthetic use.

In section 1, we motivate our survey focus on user preferences within their experiential and social context. We argue that for engagement with end-users of prosthetics to achieve its goals, it is important to understand not only preferences and dis/satisfaction with functional aspects of design, but to go further: understanding the lived experience of prosthetic use is relevant to properly identifying how technological advances can best benefit people with upper limb difference. In section 2, we describe the design, method, results and limitations of our survey. In section 3, we argue that these results support design priorities of attention to supporting users' functional capacities, reducing costs, and enabling individual choice about appearance. In section 4, we argue these results confirm the importance of recognising diversity among the limb-different population, and the need to ensure that the lived experience of disability is taken into account during the design processes. While our survey demonstrates this need, further work is needed on exactly how potential users of a

¹ The ARC funds ACES but researchers at Australian universities were responsible for recruiting the survey participants.

² Some of the below results have been reported elsewhere with a focus on engineering implications (BLINDED). Other research on the ACES prosthetic hand is reported in (BLINDED).

technology can best be engaged in research and design processes. We suggest an approach that frames prosthetic design as geared to supporting users' autonomy, understood relationally; that is, which recognises the social constitution and definition of values in terms of interpersonal relationships and mutual dependencies, and understands prosthetic use as one potential autonomy-scaffolding tool for people with limb difference.

1. Why should prosthetic designers engage with users?

Several recent technological developments allow for significant advances in the design of prosthetic limbs. The emerging field of soft robotics offers potential for the use of soft, flexible materials. Research into brain- and nerve-interfaces, combined with intelligent devices, may enable prosthetics that can be intuitively controlled via linkage to remaining peripheral nerves or even directly to the brain, and incorporating sensory feedback. 3D printing offers more precise and potentially more efficient, cheaper individual customisation. These advances in prosthetic design may present new opportunities for people with limb difference to more fully participate in society and engage in a wider range of activities.

There is a need for care to ensure that the potential of these developments best delivers benefits to people with limb difference. Assistive technology design can result in technologies that are not used by, nor acceptable to, end-users (Hocking 1999, Batavia and Hammer 1990). With regard to prosthetics, there are varying degrees of uptake. A review of studies of prosthetic 'rejection' or 'abandonment'³ estimated the overall rate of non-use of prosthetics among adults with upper limb difference at 20% (Biddiss and Chau 2007a), whilst a study by Davidson et al. (2002) indicated non-use rates of up to 56%. There is also empirical evidence that more sophisticated technologies do not necessarily lead to greater uptake (Biddiss and Chau 2007a, 239, 250; 2007b; Cordella et al. 2016).

Non-use of prosthetics can indicate a lack of fit between the prosthetics being designed and the potential recipients of these designs. This 'translational gap' (Specker Sullivan et al. 2017) is a recognised issue in relation to assistive technologies. A translational gap has financial implications – since it indicates a waste of resources, both at the level of supply of assistive devices, and at the level of misdirected research and design processes, but also ethical implications – since it indicates a failure to adequately respond to the needs of people with disability. The ethical implications are rarely emphasised in discussions about prosthetic uptake.

There are a number of ways to frame non-use of prosthetics. These framings have implications for how non-use is understood, including whether it is a problem, where the

³ We will use 'non-use' to acknowledge that some people do not reject or abandon prosthetics but rather find no need to use one.

problem is located and what sort of solution is called for. One framing positions non-use as a problem with the prosthetic user: they have failed to adapt to their situation, and/or to embrace the training needed to use a prosthetic (Messinger 2010). This implies that the solution will be to provide further support or training to improve users' skill levels and confidence (Hocking 1999). Perhaps most commonly, non-use is framed as a problem of prosthetic designs – often in terms of their limitations in best mimicking normal human form and functioning. Historically, since its beginnings in the 1800s, mass production of prosthetics has focused on replicating biological function rather than on comfort or usability (Hamraie 2017, 51). As Pullin notes, a design imperative for prosthetic limbs has been to 'reinforce reality' (2009, 35). On this framing, the solution is to make prostheses that better approximate normal human limbs in both functioning and appearance (Atkins et al. 1996; Kyberd et al. 2007).⁴

While there are benefits to providing people with limb difference with further help and training, and to resolving identified problems with existing designs (e.g., reducing weight or noise level), both framings are problematic. Framing the problem as about the user's adaptability could result in ignoring problems of both design and fitting. Framing it as about prosthetic design and mismatch with 'normality' omits the possibility that other design imperatives may be of use to people with limb difference. Further, both framings carry an inappropriate implication that prosthetic use is to be preferred to non-use, and seem to assume a medical model of disability. This model understands disability as a lack (Shakespeare 2006), such that an appropriate response is to use technology to restore 'normality' or 'normal human functioning'.

The medical model has been the subject of extended criticism from disability studies scholars. It contains assumptions that are arguably false, and are tied to norms that are discriminatory. Early disability scholars argued that disabled or 'nonnormate' bodies can be understood as different, rather than lacking, and that such differences may be valuable. People from Deaf communities, for example, have argued that deafness allows for alternative forms of experience that are themselves of value, such as the unique possibilities for self-expression and communication offered by sign language (e.g., Sparrow 2005). Further, the medical model encourages neglect of social factors which structure and shape experience, and understanding, of disability. It homogenises disability, ignoring or invalidating people's varying experiences of disability, perpetuating cultural ignorance about disability, and denying variant body experiences as valuable (Wendell 1996). In contrast to the medical model, the social model locates disability not in the bodies of people with disabilities, but in the built environment and in social norms (Shakespeare 2010). The social model introduced the distinction between impairment – physiological atypicality – and disability, arguing that disability does not result from impairment but rather from society's

⁴ This response typifies an assumption evident in engineers' approaches to perfect existing designs.

responses to impairment. On this view, someone in a wheelchair is disabled not by impaired ambulatory capacity but by living in a world of stairs, curbs without curb-cuts, and public spaces too narrow for a wheelchair (Hamraie 2017, ch 4). Communities where deafness is common provide a demonstration: in a society where everyone is able to sign, the impairment of deafness is not a disabling (Groce 1988). The social model implies then that rather than trying to change impaired bodies to fit the world, the world might be altered in ways that can accommodate people with different embodiments.

As with other conditions, individuals with limb difference have challenged the view that their condition is a lack or defect best dealt with by restoring 'normal' human physical functioning through replacing a missing body part with an artificial approximation. Some individuals with limb difference state that they are not lacking or incomplete (Frank 2000; Lapper 2006). Diana DeVries, born without arms and legs, emphasises her own ways of functioning, for example, including writing by using her residual shoulder stump to hold a pencil against her cheek (Frank 2000). Whilst this response is often expressed by people with congenital limb difference, this is not exclusively so, and is expressed by amputees also. Prosthetics were presented to DeVries, and other children in mid-century America, as non-optional in the pursuit of independence. This comes at the expense of the development of native ways of functioning, often impacting on the children's sense of themselves as autonomous agents, and reinforcing attitudes that they were lacking (Frank 2000, 52-3). Ott (2002) notes societal pressure for individuals to stand upright from 19th Century in the USA, so that middle-class people were encouraged to wear a prosthetic leg, rather than use a wheelchair, no matter the impact on their mobility (see also Gilman 2018).

Recognition of these normative assumptions invites other framings of non-use of prosthetics, perhaps along the lines of a social model of disability. We might say that upper-limb difference is only disabling insofar as there are social expectations of (two-) handedness, social attitudes flowing from these expectations, and assumptions of (two-) handedness is incorporated into built environments and designed tools. Tools created for (two-)handed bodies could be considered analogous constructed 'barriers' for people with upper-limb difference. This framing recognises that people with limb difference may not need, or may prefer not to use, any prosthetic technology, and implies non-use is not a problem requiring a 'solution'. Instead, the problem lies in the fact that other tools are designed for use by (two-)handed bodies, and fail to include those with upper limb difference.

Whilst it is important to recognise that some people have no need or desire for a prosthetic, this framing is also limited. It appears straightforwardly true of many who do not use prosthetics. But many with limb difference use prosthetics, and some people with limb difference who do not use prosthetics report that they may do so were better, more affordable, or more comfortable prosthetics available. Indeed, those who take a social

approach to disability do not typically want to rule out the use of assistive technologies entirely. Although mandated use of an assistive technology seems to communicate a desire to cover over or even expunge disabilities, this is not usually taken to imply that any use of technologies is negative. The critiques of the medical model of disability do not imply, then, that addressing the translational gap has no value; the concern is with the medicalisation of disability. In asserting this, we align our approach with that of ‘critical’ scholars who argue that disability should not be regarded as *entirely* socially constructed. Rather, disability can involve both physiological aspects, some of which may require or benefit from medical attention, and social aspects, which may be ameliorated by changes in social attitudes as well as more inclusive design of public spaces (e.g., Shakespeare 2006; Scully 2008). Garland-Thomson, for example, focuses attention on the relation between bodies and their social and material environments, which can be a relation of either fitting or ‘misfitting’ (2011). One role of technology can be to transform situations of misfit into situations of fit (2011, 596). Parens suggests taking a ‘binocular’ approach, examining disability using both medical and social ‘lenses’ to avoid a limited ‘monocular’ view and best understand disability rights issues (2014, 2017).

This theoretical approach is a good fit for consideration of prosthetic limbs, since there are different experiences of limb difference and preferences about using or not using prosthetics. In considering designing technologies for use by people with limb difference, doing justice to people’s experiences requires going beyond regarding it as solely medical or a social problem, and instead allowing for differing individual preferences. Further, the critical models focus attention on the relationship between the body of a person with an impairment, and the world, a relationship that is for some technologically mediated – in contrast to the social model’s focus on inclusive design of public spaces (Hamraie 2017).

Crucially, both social and critical approaches imply that assistive technologies should be designed in ways that take into account the lived experience of disability (Ott 2002; Pullin 2009; Hocking 1999). Scully (2008) argues that people with disabilities are a source of knowledge and emphasises the need to use the perspectives of disabled people as a starting point for epistemological and ethical exploration of disability, in contrast to the way that the conventional ‘bioethics of disability’ privileges the perspectives of outsiders to the experience. The capacity of non-disabled people to imagine the experience of disability has been shown to be severely limited (Mackenzie and Scully 2007). Garland-Thomson argues that fitting enables ‘material anonymity’; those whose bodies fit into the world thereby avoid the frictions – scenes, attention of others – involved in misfitting. This anonymity allows those who ‘fit’ to take for granted the way the world is built (2011, 597). The perspectives of misfits are in this respect more accurate; misfits are better able to identify when and how the built environment, designed tools, and social attitudes are exclusionary. Thus the experience of misfitting can produce ‘subjugated knowledges’; but recognising and drawing upon this knowledge can aid us to achieve a stronger objectivity (Harding 1993).

The mainstream perspective enforces a focus on understanding the limitations, not the capacities, of disabled people; yet the best design will need to understand both (Hamraie 2017, ch 4).

As such, empirical and experiential research involving recipients is crucial to uncover and critique the assumptions of non-disabled people – including those designing assistive technologies – and to reveal the values and goals of people with disabilities. Various methods for and ways of conceptualising such engagement have been developed (for a review see Coleman et al. 2003). These approaches share the view that researchers or designers may make decisions that draw on implicit assumptions about user experience, user preferences, disability, and the ways that technologies will be used, and that these can be brought to light and corrected by engaging with users.

There has been some research which engages with prosthetic users. Following the arguments discussed above, such engagement should ensure that end-user perspectives, and an understanding of the lived experience of (the relevant) disability, are taken into account. Available studies tend to report the views of people with limb difference on their satisfaction with particular prosthetics or problems experienced with available designs (Atkins et al. 1996; Davidson 2002; Pylatiuk et al. 2007; Biddiss et al. 2007; Kyberd and Hill 2011; Jang et al. 2011; Christ et al. 2012) or reported activities people wanted to use or had trouble using prosthetics for (Pylatiuk et al. 2007; Jang et al. 2011; Østlie et al. 2012; Lewis et al. 2012; Fogelberg et al. 2016; for a review see Cordella et al. 2016). Such studies are useful, but ultimately unsatisfactory as these points of focus limit the extent to which the engagement could meaningfully alter design approaches and paradigms. They often limit end-user input to giving negative feedback, indicating what needs to be altered but not how best to do so (Batavia and Hammer 1990). Where positive direction is elicited, there is a tendency to focus on the quantitative, functional aspects of a design (e.g., device performance), leaving the qualitative and contextual aspects of user experience (e.g., how users feel about their prosthetic) underexplored.

It is notable that although some studies set out specifically to understand user needs or experience, such studies tend to turn from this focus and end up identifying problems experienced with current prosthetics. For instance, Christ et al's (2012) survey of lower-limb prosthetic users is framed in terms of understanding user needs, but focuses primarily on dissatisfaction with current devices. Fogelberg et al. (2016) aim to understand people's experience with prosthetic feet, but their conclusions relate primarily to problems experienced rather than what people want in their prosthetics. Peerdeman et al., despite arguing for a user-centred perspective, go on to examine the views of clinicians, engineers and academics rather than users as "directly involving users in the design process may be difficult, because of differences in terminology and methodology" (2001, 720-1).

Thus despite recognition of the need for user perspectives, studies tend to focus on dissatisfaction, and to infer what users want from this. They therefore often fail to ask users what they want, prefer or need in the most meaningful way and this limits possible replies. End-user engagement is certainly difficult and it is often unclear when, how, and by whom it is best done.⁵ But it seems clear that to extract the highest benefits from advances in prosthetic design, it is important to overcome these issues.

2. Survey design and method

To build knowledge for these purposes, we designed and ran an online survey of people with upper-limb difference in Australia. The survey aimed to contribute to the evidence-based on user preferences, in a way that could expand meaningful understanding of users' preferences by seeking information on what factors influenced preferences, and the contexts in which choices were made.

2.1. Survey design

The research was undertaken by an interdisciplinary team with expertise in bioethics, engineering and biomedical device design. Questions were developed drawing on existing literature on prosthetics in engineering and in the medical humanities. Literature on prosthetics including previous surveys (cited above) was examined to identify areas in need of further or differently-focused investigation. Medical humanities literature (including the disability studies debates discussed above and qualitative and anthropological work (e.g., Murray 2009, Messinger 2010, Warren 2016)) guided identification of potential contextual factors related to prosthetic use. To avoid researcher assumptions guiding responses to the extent possible, we used open questions where feasible, and phrased questions as neutrally as possible and to the extent consistent with clarity. The survey included questions on areas already covered in existing work (e.g., dissatisfaction with existing designs) in order to contribute to updating data on the Australian population (on which the only existing study was published over 15 years ago (Davidson 2002)), and to contextualise our respondents' overall set of replies.⁶ We also requested minimal demographic information (age and sex) and information on limb difference to provide context for replies.

The resulting set of questions was arranged into sections on preferences relating to function, appearance, and sensory feedback; what sorts of prostheses people used, patterns of use, and factors affecting prosthetic use; and people's experiences of the impacts of using

⁵ Perhaps in recognition of these issues, some small exploratory studies have examined ways to investigate user experience and preferences more deeply (Schaffalitsky et al. 2009; Sansoni et al. 2016; Hofmann et al. 2016; Hussain and Sanders 2012).

⁶ In addition, several questions were included of relevance to the specific designs being developed at ACES; these results are reported elsewhere (BLINDED).

prosthetics in several domains (employment, relationships, sense of self, and others' responses).

The researchers consulted with representatives of stakeholder groups, including Limbs 4 Life Australia and Amputees New South Wales as well as individual stakeholders at several points. We met or spoke by telephone informally with representatives of stakeholder groups prior to development of questions, to discuss issues commonly experienced in Australia with obtaining and using prosthetics and identify issues of potential concern. Once the survey questions had been developed, we invited representatives to review the questions and this led to refinements and alterations.

Ethics approval was obtained from Monash University Human Research Ethics Committee (Project approval ID 8850). The survey used opt-in consent and participation was limited to people aged 18 years and over.

2.2. Method

Due to the geographical dispersion of the relevant population, the survey was run online using the Qualtrics Insight platform. A brief description of the survey, along with the link, was distributed through Australian amputee and limb difference support groups, rehabilitation centres and hospitals, researchers' universities, and professional associations of prosthetists, orthotists, occupational therapy and rehabilitation workers. The survey was open for 6 months during 2017.

Qualitative interpretation of responses drew loosely on grounded theory methodology (Charmaz 2009) as that most consistent with the discussion in section 1 and the exploratory nature of the research. Three of the researchers (MJW, BSF and EG) independently analysed the responses. Each researcher identified commonalities in the responses, which we labelled 'themes', and coded responses by theme. Themes rather than 'concepts' were examined because our concern was to build understanding of experiences and preferences surrounding prosthetic use rather than theory development. The resulting 'thematic analyses' were then discussed within the research team to reach consensus on interpretation. Coding of answers was reviewed in light of the agreed themes and most common themes identified.

2.3. Results

Participants

35 responses to the survey were received. Those that answered only demographic questions were removed, leaving 27 responses. Responses that skipped only free-text or occasional questions were retained, and below we report some answers by frequency where a question received a smaller response rate.

Characteristic	Response	n (%)
Sex	Female	17 (62.9)
	Male	9 (33.3)
	Not disclosed	1 (3.7)
Age in years (avg)	40.8	
Age in years (range)	18 - 75	
Limb difference	Unilateral right AE	6 (22.2)
	Unilateral left AE	2 (7.4)
	Unilateral right BE	5 (18.5)
	Unilateral left BE	5 (18.5)
	Bilateral (left AE, right AE)	1 (3.7)
	Bilateral (left BE, right BE)	5 (18.5)
	Partial hands and fingers	1 (3.7)
	Not disclosed	2 (7.4)
Reason for limb difference	Congenital	7 (26.9)
	Injury or trauma	5 (19.2)
	Cancer	5 (19.2)
	Sepsis/infection	8 (30.8)
	Complications from surgery	1 (3.8)
Time since limb loss ¹	Less than 3 months	0
	3 – 6 months	1 (6.7)
	6 months – 1 year	1 (6.7)
	1 – 2 years	3 (20)
	3 – 5 years	4 (26.7)
	5 – 10 years	2 (13.3)
	10 – 20 years	4 (26.7)
	More than 20 years	0
1. n = 15; this question was not displayed to those with congenital limb difference.		

Table 1. Survey participants by sex, age, limb difference, reasons for limb difference, and time since limb loss

The survey received a higher proportion of female (63%) than male (33%) respondents. The average age of participants was 40.8 years. Two thirds of participants (66.6%) indicated unilateral limb difference, and 21.6% bilateral limb difference. Just over one-quarter (26.9%) of participants were congenitally limb different. Of those who were non-congenitally limb different, 60% had lost the limb(s) within 5 years and 40% between 5 to 20 years earlier (Table 1).

Given the small sample size and online method incorporating self-selection, it should not be assumed that the sample is representative of Australians with upper-limb difference. There

is a paucity of data on the Australian upper-limb different population, prohibiting a judgement of representativeness; however the survey received a higher proportion of female respondents and a lower average age than might be expected from existing data (Limbs4Life 2011, Davidson 2002). Given the qualitative focus of our questions this was judged not to be problematic; but we note that descriptive data is presented to contextualise below responses and may not be representative of a larger population.

Prosthetic use

Just over half the sample reported owning at least one prosthetic. Myoelectric prostheses were most common, followed by hooks and body-powered prosthetics (Table 2). Five participants used more than one, and up to four different prosthetics, or used a prosthetic that fit into more than one of these categories (e.g. myoelectric or body-powered hooks).

Type of prosthetic	Participants owning only this prosthetic type	Total participants owning prosthetic type ¹
None	12 (44.4)	12 (44.4)
Cosmetic	1 (3.7)	2 (7.4)
Hook	1 (3.7)	5 (18.5)
Body powered	1 (3.7)	5 (18.5)
Myoelectric	4 (14.8)	7 (25.9)
Bebionic	1 (3.7)	1 (3.7)
COAPT system ²	1 (3.7)	1 (3.7)
Straps to hold implements	1 (3.7)	1 (3.7)
Not disclosed	1 (3.7)	1 (3.7)
1. Total > 100% due to multiple prosthetics or prosthetics that fit more than one category.		
2. This system integrates targeted muscle reinnervation and pattern recognition algorithms which interact with a myoelectric prosthetic (COAPT 2018).		

Table 2. Types of prosthetics owned by participants

Of those who owned a prosthetic, just over a third (36.3%) reported using it for less than 3 hours per day, while 40.9% reported using it for 9 hours or more (Table 3). Most participants who owned a prosthetic stated they preferred not to wear a prosthetic at some times or for some activities (86.7%, n=13) (the question was not displayed to those not owning a prosthetic). Just under two-thirds (61.5%) of participants stated they had changed the kind of prosthetic they used over time.

Average hours of prosthetic use per day	n (%)
Not usually used	1 (4.5)
Less than 3 hours	7 (31.8)
3 to 6 hours	3 (13.6)

6 to 9 hours	1 (4.5)
9 to 12 hours	6 (27.3)
More than 12 hours	3 (13.6)
Not disclosed	1 (4.5)

Table 3. Average hours of prosthetic use per day

Of the 7 participants who were congenitally limb different, only one reported owning a prosthetic; this individual reported using it for less than 3 hours per day on average. Among non-congenitally limb different participants 22.2% reported not using a prosthetic.

Participants using hooks stated these were used for a range of activities of daily living (ADLs), exercising, and work activities described as “fiddly”. Body-powered hooks were reported to be used in situations where getting wet is a possibility or where fine motor control is needed. Myoelectric prostheses were reported as being used for “all activities” by some, or for specific activities by others (e.g. “feeding and writing”). Both respondents who used cosmeses stated these were used for less than 3 hours per day.

Factors affecting prosthetic use

To understand what factors might affect prosthetic use and choices surrounding it, participants were asked to explain their answers about non-use of prosthetics and changing the type of prosthetic, and to report problems experienced with prostheses. Two main themes arose in participants’ responses.

The most dominant theme was to identify various problems with the prosthetic(s).⁷ A variety of problems with prosthetics were mentioned. Some noted problems with size and weight: the prosthetic was “heavy and clunky” or “too long and too heavy and awkward”. Some noted problems with functionality and dexterity: the prosthetic lacked “wrist flexion” or caused “clumsiness”. Some stated their prosthetic was unreliable, with tendencies to break. Some reported problems related to use and comfort, such as “[s]weating, chafing, rubbing”.

The second theme was that some participants felt no need to use a prosthetic. For example, participants reported: “I quickly adjusted to the use of my residual limb (the stump end, elbow crook) to do most activities”; and “You learn to do things [...] without it”.

Two explanations for non-use that were provided only by single participants are potentially illuminating. One person altered their pattern of prosthetic use to reflect changed self-

⁷ This would have been encouraged by the phrasing of the question on what problems participants had experienced with prosthetics. However, identifying particular problems of the prosthetic was also the dominant way participants explained non-use or changing the type of prosthetic used.

understanding: “Initially I wore a cosmetic arm until I realised I was wearing it to make others comfortable. I returned the prosthetic and went without for about 2 years”. And one participant responded to the question about what problems they had experienced in psychological rather than functional terms, reporting experiences of “frustration”.

The majority of participants (76.9%) relied on government schemes for provision of a prosthetic.⁸ The remaining 23.1% of participants had either self-funded their prosthetic, paying between \$3500 and over \$60,000; or received the prosthetic from a rehabilitation hospital.

Preferences about prosthetics

General preferences about prosthetics were gathered using a ranking task and a rating task. Free-text-response questions then asked what activities participants wanted to be able to perform with prosthetics, and for preferences about look and sensory feedback.

The ranking task asked participants to rank the importance of functionality, appearance, and affordability. These three features were chosen because functionality and appearance are the two features traditionally focused on in prosthetic design. These are difficult to achieve simultaneously on traditional fabrication methods, so that people have generally been required to choose between using a ‘passive’ lifelike prosthesis or a ‘functional’ prosthesis (Biddiss and Chau 2007a, 236-7). We also included affordability as we anticipated from stakeholder consultations that this might impose significant constraints on decision-making among the Australian population. Averages of the rankings demonstrate that overall, functionality was the most important consideration, affordability was second-most important, and appearance was ranked less important. The importance of more specific design aims was collected in the rating task, in which participants rated the importance of specific design aims on a scale (and could also provide and rate aims not suggested). Participants’ averaged ratings indicated the following design aims in descending order of importance: comfort, durability, light weight, operating lifetime, power/strength, customised size, dexterity, control interface, weight-handling, providing sensory feedback, and low noise level.

Participants provided free-text statements of what activities they considered most important to be able to do with a prosthetic. Most responded by indicating specific activities, which fell into four main themes: ADLs (e.g. cooking, eating, dressing, picking up objects); sporting and leisure activities; writing or typing; and driving. Several individual responses indicate other ways of appraising prosthetics. One participant stated a desire for

⁸ These were either state-based artificial limb schemes (61.5%), or the federal National Disability Insurance Scheme (NDIS) (15.4%). The NDIS is currently being rolled out across Australia and will eventually replace state-based schemes.

“balance”; one noted that specific activities were less important than “what it looks like”; and one noted a desire to be able to make communicative hand gestures (specifically to “flip the bird”).

Reported preferences about the preferred look of a prosthetic fell into several categories (Table 4).

Preference	Frequency (n)
Lifelike	8
Robotic/cyborg	4
Customisable	3
Skeletal/uncovered	3
Appearance unimportant	2

Table 4. Preferences about look of prosthetic, frequency

Participants’ reported reasons for preferring a lifelike look fell into two main themes. Some wanted to *blend in*, stating they preferred to look “as close as possible to normal” or to be “unnoticeable”. Others reported simply “liking” such a look. Reasons for preferring the various non-lifelike looks fell into two main, partly contrasting themes. Some participants reported wanting to *stand out*, stating that non-lifelike prostheses looked “cool” or “unique”. Others specifically wanted to avoid the prosthetic looking lifelike. One of these participants seemed to link a preference for a skeletal look to defying societal expectation for a lifelike look, in stating “I am not ashamed”. Another noted a practical reason to avoid a lifelike prosthetic: “it sometimes makes it easier if people see that the arm is different they don't become as i[m]patient”.

Participants were asked about their interest in prosthetics providing sensory feedback, particularly what sensations would be important. Again, answers fell into reasonably clear categories (Table 5). Free-text answers revealed that although most interest in sensory feedback appeared driven by functionality concerns (i.e., being able to tell when one is gripping something and how hard), others appeared to be interested in touch for its affective or sensual aspects. For example, one participant stated their reason for interest in sensory feedback as follows: “[t]he touch of someone's hand holding my hand or when I hug someone the feel of their body. To be able to pat an animal”. Both participants who stated they were “unsure” had congenital limb difference.

Sensory feedback	Frequency (n)
Grip strength	7
Feeling of touch	5
Temperature	1

Texture	1
Unsure	2
Not interested in sensory feedback	1

Table 5. Participants' views on what sensory feedback would be important in a prosthetic.

Impacts of prosthetic use

Participants were asked how much their prosthetic use had impacted on them with regard to three domains: work, relationships with family and friends, and sense of identity. For each domain, participants were asked how much impact there was on a scale from 1 to 5 (1=Not at all; 2=A little; 3=A moderate amount; 4=A lot; 5=A great deal), and to explain their answer.

Amount of impact	Frequency (n)
No impact	12
A little	1
A moderate amount	1
A lot	2
A great deal	2

Table 6. Extent of impact on participants' work situation

Participants' ratings of the extent of impact on their job or work situation are presented in Table 6. Of the 18 responses to this question, only one person stated directly that they did not work. As this respondent indicated 'no impact', this was presumably not due to upper limb difference. This suggests however that some may have reported 'no impact' as they had not previously been working. All participants who were congenitally limb different reported no impact, but among those reporting no impact there were also participants who had lost limbs between 3-6 months and 10-20 years previously. Among this group the main theme was the lack of any need to use a prosthetic at work. For example, "I find I am capable of completing any task I put my mind to without a prosthetic". A second theme was to refer to problems with prosthetics that reduced the overall benefit of wearing them at work (primarily, discomfort or lack of ease of use). This indicates that these participants might have found wearing a prosthetic at work to have value if a more comfortable one could be obtained, but work was possible without one.

Those reporting a lot or a great deal of impact had lost limbs either 3-5 years or 5-10 years previously. Among this group, responses indicate that impact could be high irrespective of whether practical results were good or bad. Some reported a high level of impact due to having *limited* capabilities or efficiency with a prosthetic, for example, a participant who stated "[I] am a lot slower in my current job [...] than [I] should be". Others reported a high

level of impact due to having *increased* capabilities or efficiency with a prosthetic, for example, “[i]t helps with a lot of things from driving to typing”.

Notably, only two respondents described the impact of their prosthetic on their ability to work in positive terms. This reflected that the prosthetic aided in activities that they valued, such as “driving” and “public speaker presence”. Dissatisfaction (with a lack of practical fit with their prosthetic and ability to work, a lack of choice of with respect to work, or wearing the prosthetic despite the ill-fit) was far more common.

Amount of impact	Frequency (n)
No impact	7
A little	3
A moderate amount	3
A lot	1
A great deal	3

Table 7. Impact on participants’ relationships with family and friends

Participants’ ratings of the extent of impact on their relationships with family and friends are presented in Table 7. Of the 7 people reporting no impact, 4 had congenital limb difference and 2 had lost limbs between 10-20 years previously (the other had lost the limb, between 3-6 months previously). Among those who stated there had been no to a little impact, explanations primarily referred to there being no need to use a prosthetic. A second theme related low impact to others’ acceptance of prosthetic use. For instance, one participant stated that “[m]ost people are fine”; while another responded by stating they are “still the same person”.

Participants who reported a lot or a great deal of impact had lost limbs either 3-5 or 5-10 years previously. Among this group, one participant again counted there to be high impact due to increased capabilities with the prosthetic: “I can now hold a glass of wine and have my residual hand free for eating”. Others noted alterations in how dependent they felt themselves to be: “I am simply not functional without prosthetics”. Two participants also reported negative effects on intimate partner relationships. One participant stated that “[the prosthetic] has made success in the pursuit of the girl [I] love more unlikely”; while another simply responded “[d]ivorce”. In this regard, two participants noted in relation to other questions that prosthetic use had negatively impacted their sex lives.

Amount of impact	Frequency (n)
No impact	8
A little	2
A moderate amount	2
A lot	2

A great deal	2
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Table 8. Impact on participants' sense of identity

Participants' ratings of the extent of impact on their sense of identity are presented in Table 8. Here, 3 of the 8 participants who reported no impact had congenital limb difference; with others' recency of loss ranging between 3-6 months and 10-20 years. Explanations of answers to these questions evidenced complex relations between participants' sense of identity, limb difference, and prosthesis use. Among those indicating no to moderate impact on their sense of identity, some explained this again with reference to not using, or needing to use a prosthetic. Interestingly, for some, this appeared to be because not using a prosthetic was *linked* to identity – "I identify as a prosthesis free amputee" and "I suppose not having worn one for a while [...] made me true to myself and be comfortable with who I am". For others, it was apparently because prosthetic use was regarded as *irrelevant* to identity – "[m]y arm doesn't define me so having a prosthetic doesn't define me either".

Those reporting a lot or a great deal of impact had lost limbs either 3-5 or 5-10 years previously. Among those reporting a lot or a great deal of impact, some linked this again to problems they experienced with the prosthetic, while others linked high impact to dependence on the prosthetic. One participant who had not been able to obtain a prosthetic noted that this too affected their "whole self". The complexity and diversity of responses to this question indicate the need for more in-depth investigation to understand these impacts.

Finally, a free-text-response question asked how others' attitudes to prosthetic use impacted on participants. Most participants stated they experienced no or very little impact, though diverging reasons were reported. Many linked it to others' reactions being on the whole positive, stating that others were "supportive", "curious", and even "in awe of it [the prosthetic]". Others indicated the lack of impact was due rather to participants' unconcern with others' reactions: "it doesn't really worry me ..." and "[m]y body, my choice!"

A minority of respondents reported experiencing higher impact with explanations linked to increased self-consciousness. One participant who had not been able to obtain any suitable prosthetic stated that people "stared" and this had led to reduced sociability. Another reported: "[i]f I put on my old prosthetic I feel like I couldn't leave the house as I'm not used to it and people would definitely know what's going on".

Limitations

A number of limitations on the survey should be noted. First, the small sample size and self-selection implies the sample may not be representative of upper-limb different people in Australia.

Second, although we consulted with representatives of stakeholder groups and people with limb difference, consultation might have been more thorough, or ideally include people with limb difference as part of the research team, as members of an advisory body or as co-researchers.

Third, our attempts to phrase questions neutrally and avoiding eliciting particular kinds of responses may have been less successful than hoped. For example, the question on preferences about look included a parenthetical “e.g., lifelike, uncovered or 'skeletal', customised design, other” for clarity. Responses received mostly adopted these terms, indicating the question might have inadvertently framed responses.

Finally, while the survey sought to understand prosthetic use and its impacts in context, many of the explanations provided by participants were brief and indicated that there was further underlying detail. Since the value of a prosthetic to someone is highly individual, qualitative research designs such as interview or focus group studies would be of value. This is especially the case in relation to the final set of questions. While our data on the impacts on work, relationships, and identity are suggestive, concepts such as identity are highly nuanced and the impacts of prosthetic use are likely to be related in complex ways to a range of aspects of self-understanding. Methods for collecting richer qualitative data undertaken with engineering and design questions in mind, will be valuable in taking user engagement further in this area.

3. Discussion

In this section, we argue that these results support design priorities of attention to supporting users’ functional capacities, reducing costs, and enabling individual choice about appearance, before examining implications for user participation and reframing the aims of prosthetic design in section 4. In prosthetic limb design, the most significant design trade-off has been between functionality and appearance (Biddiss and Chau 2007a, 236-7). Survey respondents ranked functionality as the most important feature of a prosthetic, and it has received the most attention from engineers. It is notable that despite this, only two respondents described the impact of prosthetic use on work positively, indicating that prosthetic design may be far from optimal in providing people with opportunities to work. We suggest that attention to functionality in terms of users’ lives and capacities may be of use, with recognition that whether or not prosthetic use is valuable for someone may not match able-bodied assumptions that aim to mimic or restore ‘normal’ human functioning and form. We return to this point in the following section.

Participants ranked affordability as second-most important. It is telling that even in a well-off country such as Australia, most people with limb difference are dependent on

government-provided prostheses and have a limited budget.⁹ This implies that design advances may fail to benefit people with limb difference unless designs also bring down costs.

Whilst appearance was ranked less important than functionality or affordability, appearance may still be significant for psychological well-being and acceptance of prostheses and there is growing research on the importance of the aesthetics of prosthetics (by designers and others, see for example, Pullin 2009). This is confirmed by the high impacts reported by some survey participants in relation to appearance, such as feeling unable to leave the house. Survey responses indicated preferences for both lifelike and non-lifelike prosthetics. It is often assumed in medical design that people want a lifelike prosthetic and these are more likely to be accepted by the user. A recent study by Sansoni et al. (2015) surveyed 114 respondents and showed a high correlation between attractiveness and lifelikeness, but also found attraction towards robotic and cyborg-type designs, in lesser numbers.¹⁰ That prosthetic users may have either preference (or even both) is confirmed by our survey results, with some using prosthetics with an aim of blending in – looking “normal” or “unnoticeable” – and others aiming to stand out. The preference for a lifelike prosthesis might sometimes reflect that prosthetic users themselves make assumptions in line with a medical model of disability, that is, to restore human form. Some respondents with this preference referenced practical concerns, like not having to spend time explaining themselves. This too might be interpreted as a response to social attitudes associated with biomedical assumptions that lead others to treat nonnormate bodies as curiosities. Conversely, the preference for a non-lifelike prosthetic appears to sometimes reflect rejection of the medicalisation of disability or more generally challenging social stereotypes surrounding disability. This is also consistent with findings from Murray (2009) that some limb different people deliberately choose not to conceal their prosthesis. While some of the explanations noted above are consistent with this, a preference for ‘standing out’ sometimes seemed to reflect other, more practical motives like avoiding others’ impatience.

⁹ Program details differ by state or territory, but typically limit expenditure to around \$5,000-\$8,000 every two-to-three years (Limbs4Life 2010). The NDIS does not impose a specific ceiling but allocates funds on a case-by-case basis. There are various ethical issues to consider here in relation to justice in resource provision (Limbs4life 2010). We leave these aside here since our primary focus is on user recognition in design.

¹⁰ Whilst Sansoni et al. interviewed prosthetic users, the sample included people without limb difference, at a proportion of 21% (limb-different) to 79% (non-limb-different). As such, the results for preferences are skewed to non-users of prosthetics. Interestingly, their study showed that most amputees “express attraction to devices with an interface dissimilar to a real limb” from which they concluded “there might be a characteristic in amputees that leads them to be attracted to non-realistic devices” (78). While we do not find it helpful to speculate on limb-different versus non-limb-different people’s preferences, it should certainly not be assumed that lifelikeness is always preferred.

The diversity of preferences about look demonstrate the usefulness of designs that are highly customisable at the point of supply. We would emphasise that this would be desirable not only for market but for ethical reasons, to ensure that choices about look are not driven by factors other than user choice that may respond to or perpetuate ableist assumptions. Emerging prosthetic technologies that could both reduce the need to choose between appearance and functionality, and enable more individual choice about appearance is thus a further design priority.¹¹

4. Reframing approaches to prosthetic design

In section 1, we argued that each of the available framings of non-use of prosthetics – as a problem of the user, of the prosthetic, or as no problem – is limited. Each framing captures the experience of some people with limb difference but rules out others, in some cases in ways related to problematic assumptions about disability. Survey responses demonstrate the extent of the diversity of preferences, and the complex ways that preferences relate to individual experience, perspective, and context. Approaching prosthetic design with user preferences as the priority thus requires a framing that allows for a plurality of values. These results thus confirm the usefulness in practice, in approaching design of assistive technologies, of recent focuses on the relationship between body and world, and of recognising both medical and social model perspectives. What does this imply for prosthetic designers? While we cannot hope to provide a complete answer, we here suggest an alternative way to frame approaches to prosthetic design, as involving understanding how best to design devices to support users' autonomy as an initial step in reworking how problems and opportunities are identified, and what solutions and possibilities they suggest.

We begin with non-use. Just under half of participants in our survey (44.4%) did not own a prosthetic, and those owning a prosthetic did not always use it extensively. Non-use was higher among those with congenital limb difference (85.7%) than those who had lost a limb (22.2%). Though quantitative conclusions cannot be drawn from our data, this is consistent with the expectation that people with congenital limb difference may develop other ways of functioning (Silvers 1998) and/or be more socially or psychologically comfortable with non-use of a prosthetic. These points can also be true of people who lose limbs. Reported reasons for non-use indicated that it is sometimes, or partly, driven by problems with the particular prosthetics participants owned¹² but also by the lack of need to use a prosthetic. This confirms that some proportion of the limb-different population do not experience limb difference as a problem that has the potential to be solved by technological advances.

¹¹ This might be achieved in several ways, including by allowing people to own more than one prosthetic for use at different times, via cost reduction.

¹² It is worth noting that such problems may reflect issues in fitting and rehabilitation services, rather than design issues. However, at least some factors that lowered the value of prosthetic use for participants could potentially be overcome with innovative technologies or designs.

But use or non-use are not only influenced by the nature of available devices or user responses to them. Survey responses confirm that they are also influenced by social and contextual factors, including the person's self-understanding and emotional reactions to prosthesis use. This is demonstrated by reasons given for preferences about the appearance of a prosthetic, which included not only desires to blend in or stand out for reasons of convenience or psychological/social comfort, but preferences to defy social expectations or challenge stereotypes. The role of personal experiences of disability is also demonstrated in responses to questions about impact. These revealed that decisions about non-use are sometimes linked to self-identification as "prosthesis free", regarding prosthetic use as a method of hiding one's difference, or regarding it to involve or express being "ashamed". Though only a few of our respondents reported experiencing negative effects from others' reactions, social factors including others' reactions (positive or negative) seemed to play a role in decisions: some participants wanted to use prosthetics to be "unnoticeable", or avoid what they perceived as negative (or merely irritating) attention, or conversely to use noticeable prosthetics to avoid others becoming "i[m]patient". That is, how people understood the prosthetic, and their *needs* with respect to prosthetics, were influenced by self-understanding and relations with others. These findings support work by Hocking (1999, 3) who argues that non-use of assistive devices relates to "people's perceptions of themselves as disabled and broader issues of identity" and not just to "clients' skill levels and confidence in using devices".

That prosthetic users' needs and desires surrounding prosthetics go beyond functionality is further evident in responses to the question about sensory feedback. While sensory feedback is generally sought as a means to functionality, several respondents referred rather to affect, and to desires that prosthetics could allow engagement with others (such as through hand gestures) – pointing to other kinds of 'functionality', which involve reciprocity and engagement with others. The hand is an instrument of communication and expression, not just a tool to hold things, but textbooks on prosthetic hands often limit attention to types of prehension (that is, grasping and holding of objects) (Pullin 2009, 171).

The need to recognise differences in preferences is demonstrated starkly in relation to gender and preferences about look. Gender differences have historically been invisible in prosthetic design (Hamraie 2017, ch 2). While our own survey evidenced no particular patterns by gender (and finding such patterns is perhaps unlikely given our small sample and higher response rate from females), several studies have found that male participants often prefer non-lifelike devices while female participants often prefer lifelike devices (Sansoni et al 2015, 77, 78; Murray 2009). Sansoni et al. suggest the difference in preferences may reflect differences in self-perception – that men may favour "masculine" patterns, such as robotic appearance, gaudy colours and sharp shape (78), while women may want to avoid attracting attention and/or favour designs that combine with fashion

choices, such as high heels and skirts. Qualitative studies have linked gendered preferences about prosthetics to typical gender roles that mean women are more likely to tie their identity to appearance, and men more likely to tie their identity to work or other roles connected to functionality (Matthias and Harcourt 2014; Warren 2016). Responses to qualitative interviews of Australian women amputees about their prosthetic limbs, however, demonstrated variation amongst female users and showed that women “embody and incorporate prosthetic technologies into their feminine selves in multiple, complex, gendered ways” (Grant 2015, 61): respondents expressed both a desire for prosthetics with typical female qualities, but also for going “commando” as a conscious act of subverting gendered and ableist stereotypes of women with disabilities. This preference is also shown in the views of returned female soldiers (Carter 2012). The importance for designers, also indicated by our survey results, is to recognise the diversity of preferences by users of prosthetic limbs not only between but within genders and those with gender non-conforming identities.¹³

The general point is that people’s needs and desires surrounding prosthetics are highly diverse, in part because they are contextually related to individual perspectives, and so interpreted in relation to individual understanding of social situations, needs, and relations to others – as well as to functionality. The various ways of framing non-use of prosthetics are limited then because they do not recognise the diversity of needs, desires, and understandings of prosthetic use. For some end-users, or to some extent, the problems are located quite clearly in the prosthetic; for other users, or to some extent, there is no ‘problem’; for yet others, problems may lie rather in others’ reactions, their own feelings of self-consciousness, or changing roles and relationships.

In order to aid recognition of diversity within the limb different population, we suggest reframing design approaches as aimed at developing technology that may support the relational autonomy of a person with limb difference. We first explain how a focus on autonomy can be useful in this context, and then why relational autonomy in particular provides the most apt framework.

Framing approaches to design as aiming to support autonomy can be useful in several respects. First, it offers a way of acknowledging plurality of values amongst prosthetic users. As an ideal autonomy gives normative importance to individuals’ own determination of values and conception of a good life. Focusing on autonomy thus draws attention to the preferences and aims of individual users. This supports the view that the design of prosthetics, as other assistive technologies, should attend to user perspectives, needs and

¹³ Whilst most studies assume a gender binary, Grant’s analysis brings a queer lens to the discussion. Preferences will also vary by culture both for look and with social understandings of disability and prosthetics (e.g., Hussain and Sanders 2012). Prosthetic design often ignores such differences.

values (Specker Sullivan et al. 2017, Goering 2017), while leaving room for a plurality of such perspectives. A broader aim such as supporting autonomy recognises, as Parens puts it, that “[w]e don’t have to choose between the attitude of accepting the bodies we’ve been thrown into the world with and the attitude of shaping them. Sometimes accepting the fact of disability will be wise, and sometimes exercising our creativity to change it will be” (2017, 143).¹⁴ We take this recognition to be important in relation to prosthetic limb design where the medical model still appears to be prevalent.

Second, in focusing on enabling people to undertake the activities they find valuable, the autonomy framing can help to shift attention onto using technologies to support individuals’ functional capabilities, as opposed to mimicking biological functioning. This can open up other possibilities for designers to explore alternative ways to meet functional goals. It can imply other potential avenues for prosthetics that may have alternative looks or function in ways that do not approximate ‘normal’ human physiological function, but that do enable people to undertake valued activities. Regarding prosthetics as autonomy-scaffolding tools should help shift this focus from regarding them as replacement body parts. As Goering argues in the context of neural technologies, acceptance of devices might be better achieved if they are understood as assistive; that is, users may choose or not choose to use a device that assists them in building capacities they value, as opposed to being treated with a device that is intended to fix their defect (2017; see also Mackenzie and Walker 2015 and Goddard 2017 on how relational autonomy may be either frustrated or supported by neural prosthetics). This framing, we take it, avoids the problematic normative underpinnings of the medical model, while allowing that using prosthetics, other technological aids, or non-technological aids¹⁵ may benefit those with limb difference.

It is important that autonomy is not here understood as independence from others, or from technologies. Relational conceptions of autonomy derive from the recognition that autonomy construed as independence from others is both socially and practically implausible, and undesirable. Conceptions of autonomy that conflate it with independence evoke implausible conceptions of the self (Mackenzie and Stoljar 2000). Relational conceptions seek to recognise the ways that individual selves – in the sense of practical and social identities, incorporating preferences, desires and values – are formed through and in social relationships and practices. This precludes regarding the self as even potentially ‘independent’ in such ways.

¹⁴ Parens places ‘enabling flourishing’ in a similar role, to incorporate both perspectives – the medical and social models of disability – within a binocular approach. While we do not disagree that considering people’s flourishing is useful, even perhaps the most useful focus in some questions, we think fostering autonomy is a more useful overall goal in relation to the specific purpose of prosthetic design, since it builds in consideration of individual choice.

¹⁵ Or as we might alternatively phrase it, ‘social technologies’ (Clarke 2016).

On the relational approach, autonomy is understood as compatible with various forms of dependence (Mackenzie and Stoljar 2000). This may include relationships of care with others, as well as societal provision of some kinds of resource, including both technological and other techniques of support. The relational approach to autonomy conceives of our agential capacities generally as socially scaffolded: all of us rely on others myriad ways to enable us to act, including to act autonomously. Relational conceptions of autonomy seek to do justice to the normative importance of individuals while recognising the social embeddedness of selves, and the importance of social scaffolding in fostering autonomy (in contrast to the traditional tendency to regard social relations and socialisation as threats to autonomy) (Mackenzie 2010).

This approach is apt for thinking about prosthetics as autonomy-scaffolding tools. We can extend the relational approach with the recognition that it is not only socially but materially that each of us depends on our environments (Garland-Thomson 2011). As Reynolds argues, one's body is only one component of what is required to complete any action: we also require there to be a world in which we are able to act, and that supports one's body in the ways that enable it to act. Being able to run 5 kilometres requires not only certain bodily abilities, but "a host of natural and social conditions, from proper running gear to navigable paths to a nontoxic environment. It also depends on the conditions of my upbringing and labor: what I was or was not exposed to as a child and the types of demands my economic situation places on my lungs and immune system" (2018, S33). That is, while a limb-different person might rely on prosthetic technologies to run 5 kilometres, we are all dependent on some social and material conditions if we are to have this ability. The relational approach to autonomy can thus include the materially-focused point that abilities are constituted not solely by a person's organic body, but also by tools, the environment, and other people. Prostheses are one way, among many others, that organic bodies are enabled to perform actions; someone's abilities depend not simply on what their limbs and so on are like, but on how their body interacts with its environment, and how that environment supports or fails to support bodies to interact (Reynolds 2018, S34).¹⁶ This perspective encourages attention to the contexts of use of a prosthetic limb, and its interactions with other tools as well as other objects in the environment.

A framing that asks designers to consider how potential prosthetics can best support autonomy, understood as involving relations of dependence, thus has a number of benefits: recognising a plurality of values, shifting attention to supporting functional capacities, and encouraging consideration of contexts of use and interfaces between the prosthetic and other tools. This cannot be done without foregrounding disability and user perspective in

¹⁶ This has implications for prosthetic provision, since it implies that abilities can depend on how well one's social environment enables access to tools that support abilities. We focus here though on design.

design. End-user perspectives are necessary to uncover when design decisions are being influenced by assumptions about their needs and desires, rather than by meeting actual needs and desires in ways that can scaffold autonomy.

5. Conclusions

Advances in prosthetic design present new opportunities for people with limb difference to both more fully participate in society as well as to address issues related to identity and social understandings of disability. At a time when technological advances are beginning to make ‘mass customisation’ a possibility, there is an opportunity to move on from the ableist assumptions that have formed part of design approaches since mass production of prosthetics began. Proper attention to users’ needs and preferences presents opportunities to best harness these opportunities. The survey reported here contributes to knowledge about prosthetic users’ preferences and indicates the importance of recognising diversity of preferences, and more generally, of attending to the full lived experience of people with disability. Rather than approaching prosthetic design with the aim of ‘fixing’ either prosthetics, or users’ responses to them, we have suggested framing prosthetic design as a matter of supporting users’ autonomy, and so of understanding how prosthetics can best support agential values and capacities. Further work is needed on how an understanding of user experience in terms of the social placement of disability can best be taken into account during design processes.

In particular, the research and argument presented here demonstrate the benefit of research attention to new objects of focused research. It is important to attend to the lived experience of people with upper-limb difference, to better understand user needs and preferences, and identify relevant ‘subjugated’ knowledge. It is also important to recognise the context of use of prosthetic technologies, including in its social aspects and with regard to what other technologies prosthetics are used to interact with. Recognising the impact of individual understandings of the role of technology and interpretations of disability is also needed to avoid misunderstanding decisions about prosthetic use. These topics of research might be best examined in qualitative methodologies able to engage with particular users in some depth, particularly at an exploratory stage of research. Our argument also has methodological implications for both qualitative and quantitative studies. How people’s capacities, and not merely limitations, can be better understood is unclear, and many prosthetic users themselves may tend to focus on reporting problems, rather than positive capacities that might be leveraged by technologies, when interacting with researchers. Increased consultation with or ideally co-design of studies with users may be of use in this regard. There is also a need for better understanding of other influences on design approaches, among designers working in different contexts (e.g. at government-funded research institutions and in industry), and how user engagement can be incorporated into existing practices.

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