Centre for Everyday Life
Murdoch University

“Connecting, supporting and empowering young people living with chronic illness and disability: The Livewire online community”

Livewire Research Project:
Final Report to the Starlight Children’s Foundation
October 2009

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Contents

1. Summary 2
2. What is Livewire? 3
3. Overview of the Livewire Research Project 4
4. Methodology 5
5. Contexts 9
6. Analysis 20
7. Future Research 41
8. Summary of Findings 42
9. References 46
10. About the Authors 50
11. Acknowledgements 52
1. Summary

This report summarises the key findings of the nine-month research project into the ways that members use the Starlight Children’s Foundation’s Livewire online community, and the impacts of Livewire on their wellbeing, their sense of identity, and their sense of embodiment. It builds upon a preliminary report that was submitted to Livewire in July 2009.

The research found that the Livewire online community powerfully supports the personal and social wellbeing of its members.

It achieves this by helping members to overcome the social isolation that is often experienced by young people who have limited opportunities for socializing with others their own age due to limited mobility, long periods of time spent away from school, either in hospital or at home, and so on. Livewire enables young people living with a chronic illness or disability to experiment socially in a safe, moderated setting. These factors in turn foster meaningful friendships – with many Livewire members reporting that they count their Livewire friends amongst their closest and most dependable friends – and a high level of peer support among members. Livewire members report that Livewire is a space in which they not only have fun but also make important life decisions in a supported environment. Livewire friendships balance members’ need to ‘be a normal kid’ with their need to interact with other young people who can relate to their circumstances.

As such, Livewire provides its members with a reliable point of social connection, particularly when their lives are disrupted and encourages them to form strong, meaningful and enduring friendships in a safe online environment.

The social connection, sense of friendship and community, and safety that are nurtured in the Livewire context contribute directly to members’ enhanced sense of wellbeing, as well as building their capacity to:

- adapt to adverse life circumstances, overcoming anxiety and stress
- accept their illness or disability
- engage and form meaningful relationships with others, feeling a strong sense of belonging
- live full lives

The result is that Livewire helps empower members to make the very most out of life.

Chat continues to be one of the key attractions of the Livewire community. The variety of online, moderated chat provided by Livewire is unique and highly successful in fostering a sense of community amongst its potentially socially isolated adolescent members. Members consistently reported that Livewire chat is what attracts them to the community. However, in conversations with members, it also became obvious that Livewire chat is much more than ‘chat’. Livewire is a community. Chat hosts are fundamental to the success of the Livewire community. Chat hosts are active participants and much more integrated into the community than in other online chat spaces, directly engaging in conversations and ‘making fun’ with the members. Because of the unique role played by Livewire chat hosts, Livewire is able to provide an entertainment space in which young people are encouraged not only to talk and form friendships, but also to engage in structured games and competitions, providing them with a sense of fun, camaraderie and belonging.
Livewire chat does not operate in isolation from the other components of the Livewire interface. Rather, chat is successfully integrated with the games, blogs, members profiles, and news and entertainment features of Livewire, meaning that, while they often report that chat is their favourite Livewire feature, the majority of members actively engage with all of the other features of Livewire on a regular basis.

*Report Structure:* This report begins by describing what Livewire is and explaining the scope and methodology of the research project. We then move to an analysis of the data generated by the research project. We focus first of all on Livewire members’ broader patterns of online and networked technology use, comparing them to general trends in young people’s technology use. This discussion provides a framework within which to interpret the findings specific to Livewire.

We then discuss in depth the various impacts of Livewire on the wellbeing of Livewire members. This discussion addresses a series of key areas that we have identified as central to the way Livewire works to support young people living with chronic illness, a serious condition or a disability. These are:

- Livewire chat
- Livewire chat hosting
- Online friendships and community
- Online safety and moderation
- Embodiment and identity

Finally, we propose a series of future research areas.

In the course of the research project, many of our findings replicated those of studies conducted elsewhere. However, the project also foregrounded a number of new findings, along with key points of difference from other research findings. As such, we have highlighted these in summary tables throughout the report.

## 2. What is Livewire?

‘Connecting, supporting and empowering through online communities’

Livewire is an online community connecting young people aged 10 – 21 years old living with a serious illness, chronic condition or disability, to help increase their social inclusion and enhance their sense of connection and community.

Livewire facilitates connection, empathy and understanding between people who are experiencing similar situations by offering a customised, safe and secure online community featuring social networking tools and relevant content, including:

- online chat
- blogging
- member profiles
- games
- music
- articles
- community forums
- competitions
Livewire aims to lift spirits, enhance self-esteem and build resilience. And importantly, Livewire is about having fun.

Livewire members undergo a strict signup and identity checking procedure, meaning that its members are guaranteed a high level of safety. Livewire chat forums and content are moderated seven days a week by professionals trained in adolescent health. These features mark Livewire’s key points of difference from other social networking sites such as Bebo, Facebook and MySpace.

There are two age groups inside the larger Livewire Members Community: 10-15 years and 16-21 years. Members thus interact and socialise with other young people of the same developmental age.

Livewire also recently launched a ‘Siblings’ community and a ‘Parents’ community.

Livewire is a wholly owned subsidiary of the Starlight Children’s Foundation and is supported by funding from the Australian government’s Clever Networks program.

3. Overview of the Livewire Research Project

This research project addresses the Livewire/Starlight Children’s Foundation’s following areas of research priority:

• Social networking and engagement
• Experiences of Livewire compared to other social networking sites
• Formation of social identity

Deploying a holistic approach, this project gives Starlight Children’s Foundation an insight into:

• how young people use social networking in the context of their daily lives
• how young people living with chronic illness and disability physically engage with technologies
• the relationship between young people’s online engagements and their friendship and support networks
• the ways Livewire participants use Livewire in conjunction with other forms of online networking and support
• how the above situate Livewire in relation to other existing social networking sites

Using a predominantly qualitative research framework, the proposed project identifies the key factors shaping young people’s online engagements, with an emphasis on the particular and everyday needs of young people living with chronic illness and/or disability. We focus upon socio-cultural factors, technological factors, embodiment factors, and material-cultural factors.

The research project proceeds in four phases:

**Phase 1:** Preliminary Research Phase

**Phase 2:** Online Research Phase (online surveys, online focus group discussions and website content analysis)

**Phase 3:** Ethnographic Research Phase (participant observation visits)

**Phase 4:** Reporting Phase
4. Methodology

The following outlines the methodologies underpinning the research project:

4.1 Phase 1: Preliminary Research Phase
The first phase of this project entailed a research audit of scholarship encompassing the areas of:

- deploying young people’s use of mobile media as a means of enhancing their sense of social inclusion and connectedness
- processes of identity formation in relation to online and network technologies
- transformations in the significance of ‘community’ in the era of online and network media
- the use of online media by sufferers of chronic illness and disability
- the human-technology relationship
- user-led design and participatory design for online and network media initiatives for young people
- the phenomenology of technological engagements (the analysis of the embodied experience of technology usage)
- young people’s mental health and wellbeing, and the promotion of resilience using online and networked technologies

The research team drew upon this material to shape the subsequent phases of the research and to evaluate the findings.

4.2 Phase 2: Online Research Phase (online surveys and online focus group discussions)

- Online Surveys
  The research team designed an online survey into the media and technology practices of young people living with chronic illness and/or disability. Approximately 35 participants were recruited via the Livewire site. This online survey, comprising approximately 50 questions and conducted through the Livewire site, generated baseline information regarding the demographics of Livewire’s current participants, as well as basic information about their technology usage patterns, their medical condition or disability, and their engagement with social networking interfaces. An Opinio survey software license was purchased to carry out this phase of the research.

- Online Focus Group Discussions
  The research team conducted four hour-long online focus group discussions with between one and six participants each (total of fourteen participants), with the aim of eliciting further information about the cohort’s attitudes towards social networking and media and technology and their existing online and face-to-face friendship networks. Participants were recruited from within the group of survey respondents in order to represent the range of Livewire’s current active participants. Online focus group discussions were conducted via the Livewire chat facility in order to engage participants in a forum with which they were familiar, and to allow the researchers to observe the ways participants engaged with the interface and interacted with one another within the chat facility.
• **Livewire Website Content Analysis**
  The research team undertook a content analysis of the Livewire site in order to evaluate the kinds of content that are currently being generated by participants, the purposes for which participants use the site, the opportunities for community building and social networking implicit in the site, and how the Livewire site delivers on Starlight Children’s Foundation’s vision for the Livewire community.

  The results of the online research phase were used to identify and prioritise the range of issues that were addressed in the Ethnographic Research Phase (Phase 3).

4.3 Phase 3: Ethnographic Research Phase (Participant Observation Visits)

In this phase of the research, we undertook 18 x 1.5 - 2 hour participant observation visits to Livewire participants in their place of residence. We interviewed participants in capital cities, regional centres (e.g. Newcastle, NSW and Ballarat, Vic) and semi-rural locations in Victoria, New South Wales, and Queensland. Our sample included participants across a range of illnesses/disabilities, age, gender, socio-economic status. Livewire members received a $150 retail gift voucher for their participation.

The idea of these visits was to meet with participants face-to-face in the place where they normally access the Internet and to observe their online engagements in process. The interviews took the form of semi-structured informal conversations, followed by 30 minute ‘technology walkthroughs’ in which researchers asked participants to log on and show them how they used the Internet. Our researchers deployed participant observation methods to ensure these interviews were as friendly and non-intrusive as possible.

<table>
<thead>
<tr>
<th>Primary Methodologies Deployed for Phase Three</th>
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<tbody>
<tr>
<td><strong>Ethnography</strong> - involves the study of small groups of people in their own environment. That is, rather than looking at a small set of variables and a large number of subjects (‘the big picture’), the ethnographer attempts to get a detailed and ‘deep’ understanding of the circumstances and everyday practices of the group being studied. Ethnography is based on qualitative methods (e.g. detailed observations, fieldwork, structured and unstructured interviews, analysis of transcripts, participant observation). Ethnography provides an ideal way of understanding young people’s physical engagements with the various technologies they use, as well as how they engage in the practice of social networking. Using ethnography enables researchers to get a holistic picture of young people’s technology use in practice.</td>
</tr>
<tr>
<td><strong>Participatory design</strong> - is motivated by a commitment to both the usability and usefulness of technology, on the one hand, and to active user-participation in technology design, on the other hand. It involves users in the design process as co-designers by empowering them to propose and generate design alternatives. The essence of the participatory design approach is to develop mutual trust and respect and effective communication and collaboration between all parties involved in or affected by the design. Participatory design engages with users in their own context and develops early prototypes that users can evaluate, understand, appropriate and interrogate from within their own contexts and practices. In this phase, we used some of the techniques deployed in the initial stages of participatory design processes to identify and evaluate the particular user interaction needs of the Livewire cohort.</td>
</tr>
</tbody>
</table>
In these interviews, the researchers:

- undertook a ‘cultural probe’ in which participants were asked questions to elicit information about how they conceptualise their online and network communication activities in the context of their everyday lives. Among other things, we were interested in:
  
a) understanding the scope and role of social networking as a means of engaging with peer communities where participants are limited by their illness and/or disability in their opportunities for socializing.
  
b) understanding the ways their self-conceptualisation (as, for example, ‘sick’ or ‘recovering’) and their stage in recovery impacts upon their identification with the Livewire site and the corresponding Livewire community. That is, we are interested in how participants’ identification as a young person living with chronic illness and/or disability shapes the nature and extent of their engagement with Livewire as opposed to other social networking sites.

- analysed the arrangement of the physical space in which the participant engages online, taking note of the particular physical constraints experienced by the participant and the physical ‘dialoguing’ between the participant’s various communication technologies and (where relevant) assistive technologies. We undertook a ‘technological probe’ to ascertain how participants experience the technical aspects of the various interfaces they interact with and how they might integrate technologies differently from other young people. This approach was complemented by ‘embodied interaction’ and ‘user interaction’ analyses. Human-computer interaction (HCI) has long been used to develop technologies that are ergonomically and culturally appropriate. However, as recent scholarship has pointed out, HCI frequently makes assumptions about computer users’ physical embodiment. ‘Embodied interaction’ (cf. Lucy Suchman, Paul Dourish) moves beyond the assumption that the body is universal to account for the impacts of specific contexts, cultures and bodies. In particular, we were interested in the impact of various levels of physical mobility, motor function and energy levels on the choices participants make about the kinds of technologies and forums they interact with. A ‘user interaction analysis’ identified the range of problems these young people face in engaging with technologies.

- asked the participant to walk the researcher through the range of technologies and interfaces they deploy in the course of a normal day in order to analyse the impact of cross-platform engagements (computer, mobile phone, games consoles, web, face-to-face and so on) on the structuring of participants’ communication practices. This information enabled us to observe the cross-platform and a medium specific factors shaping how and why Livewire participants communicate through particular media and the impact of this on their social networking practices.

- undertook a ‘handbag analysis’ of the kinds of information participants store on their computers and asked them about why they think it’s important to store this kind of information in order to help us understand the place of digital content in shaping their identities as both individuals and members of online, mediated and ‘real world’ communities.
4.4 Phase 4: Reporting Phase

In addition to this report, this project has produced the following material outcomes:

1. Preliminary Report to Livewire: A 20 page report outlining the preliminary results from the Online Research Phase

2. 2 x Journal Articles (in production) to be published in relevant international, refereed, academic journals (these articles will also be adapted for publication in industry journals)

3. Online Survey Statistics
   Statistical data pertaining to Livewire members’ use of online and networked media technologies, their friendships and social networking practices, their medical condition or disability, and how it impacts upon their engagements with technology

4. 2 x Presentations to Livewire staff to communicate the results of this research project

5. 2 x Conference Presentations

6. 1 x Summary Report in plain language to aid Livewire in communicating the results of this project and securing future research funding for the Livewire project

7. Press releases and promotional articles in relevant publications

4.5 Recruitment

At the time of commencing this research project, the Livewire community had a total of 462 fully validated members. All participants for Phase 2 and Phase 3 were recruited from within this existing membership.

At the beginning of Phase 2, Livewire members were invited via the Livewire site to participate in an online questionnaire. Letters were sent to all Livewire members and their parents, as required by Murdoch University ethics approval processes. These letters alerted members to the survey, explained what the research entailed and how the results would be used. Members were offered a chance to go in a draw to receive a retail gift voucher for participating. Fifty two participants completed the questionnaire. This constituted approximately 11% of the total Livewire membership as at March 30, 2009, which is a typical response rate for this kind of recruitment process. The majority of survey participants were aged 14-16 (40%), with 20% male and 80% female. Given the unavailability of precise data pertaining to the gender composition of the Livewire membership at the time of commencing the study (members were not required to specify their gender when signing up until recently), it is difficult to say whether the survey sample accurately represents the gender balance within the Livewire community. It appears that females outnumber males in the Livewire community (60:40 based on available data). However, given that females generally show a greater willingness to participate in surveys, it may be assumed that this sample is skewed towards female respondents. In terms of age brackets, this sample is representative.
All participants for both the online focus group discussions (second part of Phase 2) and the participant observation home visits (Phase 3) were recruited from the pool of survey respondents.

Following completion of the online survey, invitations were sent to survey respondents asking them to participate in online focus group discussions. Participants were offered a $25 retail gift voucher in return for participating in an hour-long focus group discussion via the Livewire chat facility. Parental consent for the participation of minors in the study was obtained by the Livewire team, as stipulated by Murdoch University ethics approval. A total of 14 members (including 3 x male and 11 x female) from across the 10-21 age bracket and a representative range of geographical locations (both urban and regional) participated in these focus group discussions.

In Phase 3, all members who had responded to the online survey were contacted to ascertain their interest in participating in the participant observation home visits. Participants were offered a $150 retail gift voucher for their time. The research team conducted a total of 18 x 1.5-2 hour participant observation home visits. This sample included a representative range of geographical locations, age groups and gender (3 x males and 15 x females). It should be noted that the majority of the participants in Phase 3 were long-term members of Livewire (over 12 months), with approximately half of the total participants having been members of the original Livewire pilot.

5. Contexts

This section (Section 6) describes the contexts shaping members’ engagements with Livewire. We begin by outlining the age, gender and geographical composition of Livewire membership, along with recent growth in the community. Section 6.2 explains Livewire participants’ general use of both information and communication technologies (ICTs) and online social networking, and Section 6.3 describes their use of other media, including both traditional and online media. This section thus contextualises our later discussion of members’ use of Livewire.

5.1 Livewire Membership – Composition and Growth

In order to become a fully validated member of Livewire, an individual must go through a rigorous signup process, including obtaining parental consent and a three-point identity check.¹

As at March 30, 2009, the Livewire community had 462 fully validated members (ie: members who have been through the full signup process) with the following state and gender breakdown overleaf:

¹ Livewire has three levels of membership. All members of Livewire are aged between 10 and 21 years old. A Fully Validated Member is a young person who has indicated that they have a serious illness, chronic health condition or disability and has returned their parental consent form and had their identity verified. A Partially Validated Member is a young person who has indicated that they have a serious illness, chronic health condition or disability but have not returned their parental consent form and had their identity verified. A Registered Member is young person who has indicated that they do not have a serious illness, chronic health condition or disability.
State Locations Breakdown (as at March 30, 2009)

<table>
<thead>
<tr>
<th>Group</th>
<th>ACT</th>
<th>NSW</th>
<th>QLD</th>
<th>SA</th>
<th>TAS</th>
<th>VIC</th>
<th>WA</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10-15 yrs)</td>
<td>13</td>
<td>106</td>
<td>36</td>
<td>4</td>
<td>3</td>
<td>38</td>
<td>20</td>
<td>220</td>
</tr>
<tr>
<td></td>
<td>6%</td>
<td>48%</td>
<td>16%</td>
<td>2%</td>
<td>1%</td>
<td>17%</td>
<td>9%</td>
<td>100%</td>
</tr>
<tr>
<td>Older</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16-21 yrs)</td>
<td>22</td>
<td>99</td>
<td>45</td>
<td>10</td>
<td>2</td>
<td>45</td>
<td>19</td>
<td>242</td>
</tr>
<tr>
<td></td>
<td>9%</td>
<td>41%</td>
<td>19%</td>
<td>4%</td>
<td>1%</td>
<td>19%</td>
<td>8%</td>
<td>100%</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>205</td>
<td>81</td>
<td>14</td>
<td>5</td>
<td>83</td>
<td>39</td>
<td>462</td>
</tr>
<tr>
<td></td>
<td>8%</td>
<td>44%</td>
<td>18%</td>
<td>3%</td>
<td>1%</td>
<td>18%</td>
<td>8%</td>
<td>100%</td>
</tr>
</tbody>
</table>

* Data provided by Livewire Membership Team

Gender Breakdown (as at March 30 2009)

<table>
<thead>
<tr>
<th>Group</th>
<th>Female</th>
<th>Male</th>
<th>Not nominated</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10-15 yrs)</td>
<td>67</td>
<td>48</td>
<td>105</td>
<td>220</td>
</tr>
<tr>
<td></td>
<td>30%</td>
<td>22%</td>
<td>48%</td>
<td>100%</td>
</tr>
<tr>
<td>Older</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16-21 yrs)</td>
<td>60</td>
<td>37</td>
<td>145</td>
<td>242</td>
</tr>
<tr>
<td></td>
<td>25%</td>
<td>15%</td>
<td>60%</td>
<td>100%</td>
</tr>
<tr>
<td>Total</td>
<td>127</td>
<td>85</td>
<td>250</td>
<td>462</td>
</tr>
<tr>
<td></td>
<td>27%</td>
<td>18%</td>
<td>54%</td>
<td>100%</td>
</tr>
</tbody>
</table>

* Data provided by Livewire Membership Team

Following a lengthy pilot and development stage, Livewire was relaunched in April 2009. As of October 21, Livewire had an impressive 3400 members, including 1381 fully validated members, 1120 partially validated members and 899 registered members. The following graphs show current membership statistics.
Livewire membership is concentrated in New South Wales. This in part reflects larger population numbers in New South Wales, but also appears to be a product of the excellent working relationship Livewire has developed with Westmead Children’s Hospital, as well as the rollout of technology in hospitals during the Livewire pilot phase (NB: the pilot was carried out in NSW). As Livewire continues to grow and develop relationships with hospitals and introduce more technology and enhanced Internet access in hospitals in other states, it is expected that membership statistics will more accurately reflect regional population numbers.

It is noteworthy that Livewire membership is currently skewed in favour of young women. Research shows this is typical of social networking sites: girls are more likely to use media and computer technologies for communication purposes, and to take part in social networking than boys (Turkle, 1998; Turkle, 2005). However, statistically, young men are more prone to poor mental health (Australian Bureau of Statistics, 2007; Coffey et al., 2003a; Coffey et al., 2003b; Hall et al., 1999; Teesson et al., 2000) and are less likely to seek help when going through difficult times (Möller-Leimkühler, 2002; Chandra & Minkovitz, 2006; Rickwood et al., 2007). Recent research argues that health policy and services should investigate opportunities to promote mental health through the kinds of settings and activities in which young men normally engage (Herrman et al., 2005), such as online forums. Given this, Livewire might look to pursue more explicit gender-based strategies to attract a greater number of young men to the community, and support their engagement.

5.2 Participants’ Attitudes Towards and Use of ICTs and Social Networking

Research shows that the character of young people’s online and networked engagements has undergone a significant shift since the early- to mid-1990s. As Valkenburg and Soeters (2001) note, in the 1990s, young people used the Internet primarily for entertainment purposes. Since the advent of Web 2.0 platforms however, increasingly young people use the Internet for interpersonal
communication (Gross, 2004; Lenhart, Madden and Hitlin, 2005) and the production of user-generated content² (Richardson, Third and MacColl, 2007).

In particular, the last few years have witnessed the rise of the ‘personal web’, “a collection of technologies that confer the ability to reorganise, configure and manage online content rather than just viewing it” in a manner that “explicitly supports one’s social, professional, learning and other activities via highly personalised windows to the virtual world” (Horizon Report, 2009). Young people have been at the forefront of personal web adoption patterns worldwide and the Horizon Report – an annual report into global technological trends and uptake – predicts that this will consolidate over the next two to three years internationally (2009). It thus appears that social networking will remain central to young people’s online engagements into the future.

5.2.1 Livewire Participants’ use of the Internet

If the Internet is an increasingly prominent and important feature of young people’s everyday lives in general, and if social networking is becoming an integral part of young people’s lives globally, for Livewire participants, this is particularly pronounced.

One participant described the Internet as ‘my lifeline’ and numerous others stated that they would ‘die without it’. The Internet provides them with a consistent point of connection with a stable world, especially when their lives are disrupted due to periods in hospital, long periods spent at home, or when mobility – getting ‘out and about’ – is an issue. When, in the course of the online discussion groups, we asked participants which technologies they would take with them if they were moving to a desert island, the overwhelming majority nominated the Internet/computer with a wireless connection as their first choice.

Results from the online survey showed that all participants spent considerable time online (the majority spending up to 4 hours a day). Whilst they used the computer and Internet for a range of different purposes, chat, social networking and email were identified as the most important Internet/computer-related tasks. This suggests that this cohort is typical of the shift towards using the Internet predominantly for interpersonal communication. After chat, social networking and email, participants used the Internet/computer for homework, downloading music, searching for content and transferring data. Notably, none of them used the Internet to search for medical information or support services. In fact, many expressed a disinclination for using the Internet for this purpose and a number of participants identified the fact that Livewire was ‘not about being sick’ as one of the strengths of the site.

Participants’ general attitudes towards use of media and communications technologies revealed a clear sense of agency and ‘mastery’, particularly in terms of the enabling effects of computers and the Internet. The literature on disability and online and networked technology usage demonstrates that the Internet enables a sense of mastery and control of the communicative environment, and can often facilitate a sense of achievement and satisfaction. This is supported by a number of studies; as Lupton et al note, when asked about the technologies they used, participants in their study (people living with severe disability) “evoked the idea of the pleasure of mastery, the joy of accomplishment. In dealing with a sociocultural

² User-generated content is one of the characteristics of the shift to Web2.0. In a Web 2.0 environment, ‘users’ are no longer just passive consumers but have transformed into ‘produsers’ (Bruns & Jacobs, 2006). User-generated content refers to content that is produced by users and then uploaded to the Internet for sharing with peers, friends, family or the public.
context in which they tend to be positioned as ‘helpless’, ‘passive’ and ‘dependent’, achieving this mastery and competence is vitally important to their sense of self” (2000: 1857). When asked to imagine an ‘ideal’ technology they would most like to see invented, one participant (a self-proclaimed computer expert), wanted ‘connectivity everywhere’, while another said he would like to ‘live inside a computer’. Two female participants we spoke to during the online focus group discussions expressed a strong sense of achievement and satisfaction with the fact that the Internet (and the Livewire online community in particular) provided them with an opportunity to share their creative writing outputs with others. Two male Livewire participants spoke at length and very proudly of their technological expertise with the Internet, indicating that their Internet usage leads directly to the kind of mastery and control identified in the research.

<table>
<thead>
<tr>
<th>Existing Research on young people’s use of the Internet</th>
<th>Livewire Research Project Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Internet plays an increasingly central role in young people’s lives globally.</td>
<td>Internet usage is of particular importance and pertinence to the Livewire members.</td>
</tr>
<tr>
<td>Young people use the Internet primarily for interpersonal communication.</td>
<td>Livewire participants use the Internet primarily for interpersonal communication.</td>
</tr>
<tr>
<td></td>
<td>Online communication provides Livewire participants with a reliable point of social connection when their lives are disrupted by periods in hospital or at home, or when mobility is an issue.</td>
</tr>
</tbody>
</table>

5.2.2 Physical Factors Impacting Livewire Participants’ use of the Internet

Analysis of the relationship between disability and/or chronic illness, online and networked technology use, and wellbeing constitutes a relatively new area of research inquiry. However, there is a recognition within this literature that when studying how new technologies might enhance the everyday lives of the chronically ill or disabled, we must be wary of overrating the liberating potential of new technologies. Given that the majority of communication and media technologies presume an able body – that they are not neutral for all users – it is important to assess the limits imposed by issues of embodiment in order to ascertain to what extent technologies can enable the chronically ill and the disabled. As Gerard Goggin notes, “our taken-for-granted technologies can be enabling or disabling according to the norms that are built into technological systems (too often just assumed to be either inherently good or value neutral)” (2006: 310).

3 “Personal well-being measures people’s experiences of their positive and negative emotions, satisfaction, vitality, resilience and self-esteem and sense of positive functioning in the world. Personal well-being is broken down into five main components with a number of subcomponents: emotional well-being (positive feelings and absence of negative feelings); satisfying life; vitality; resilience and self-esteem (self-esteem, optimism and resilience); and positive functioning (which covers autonomy, competence, engagement, and meaning and purpose). Social well-being measures people’s experiences of supportive relationships and sense of trust and belonging with others” (New Economics Foundation, 2008).
Similarly, Lupton notes that “technologies have the potential both to exacerbate disability and to enhance selfhood and embodied capacities” (2000: 1860).

In the course of the online focus group discussions, we became aware that, for a small number of participants, the technology presented some difficulties. Some participants were much slower to respond to questions, indicating that they experience difficulty undertaking basic data entry tasks. Furthermore, issues of access clearly impact participants’ capacity to engage effectively in online communities and forums. A small number of participants logged on via dialup, which appeared to impede their ability to contribute to the discussion. And lastly, a couple of participants experienced technical difficulties logging on to the site. However, despite these issues, it became very clear that this cohort are generally very adept users who have, where necessary, developed effective ‘workarounds’ to accommodate their particular physical limitations.

Of those we interviewed in Phase 3, very few (approximately three out of a total of eighteen) had illnesses or disabilities that seriously impacted their ability to access and use online and networked technologies. Of these, it is noteworthy that none used specially modified equipment (eg: voice activation, modified keyboards etc) to assist them. Rather, all of them had developed highly effective workarounds that entailed adapting the physical body to the media and communications technology (rather than adapting the technology to the body). Participants with limited motility in their hands had become incredibly adept at typing with two fingers (with one participant’s parent describing – with great pride – his son’s typing as ‘like watching an octopus on the keyboard’). In some cases, participants did experience some physical difficulties using technologies. For example, several did not have the motor control to use mobile phones for the purposes of texting. Some also had difficulty holding a conventional telephone handset. However, all the participants demonstrated a relative ease with using computer keyboard and mouse technologies. In at least three instances, participants reported having difficulty writing with a pen, preferring keyboard text-based communication as a result.

Notably, several participants with limited motility said that, as the traffic in the Livewire chat space has increased over the last few months (with numbers having increased from approx. 5 people to up to 15 people at any one time), it has become more difficult for them to keep pace with the conversations and respond in a timely manner because the screen scrolls at a greater speed. Two participants explicitly stated that they sometimes found the faster pace of recent chat sessions a bit tiring and reported that they sometimes ‘just sit and watch and only comment when I have something really important to say’.

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4 ‘Workaround’ refers to habits developed in order to circumvent physical, mental, or technological difficulties in performing a particular task.

5 Motility refers to motor functions (in this case, we use it to refer to the positioning of the hands and the body) whilst the body is stationary.
Case Study: Andrew  
**Technology enabling active participation**

Walking into Andrew's place, it seems like any other 'normal' suburban home. But what about the lift well? That's not quite usual. Or the high-wear commercial office carpet, the widened doorways, or the two or three computer network points in each room? And that's before you get to his bedroom 'console': 11-year-old Andrew, who uses an electric wheelchair because of his cerebral palsy, is master of a range of communication technologies.

His personal devices include a laptop, netphone, mobile phone, intercom and iPod nano, among others. He can't write with a pen but knows how to log into his grandfather's computer 500 miles away, in order to remotely fix software problems for him.

In exchange, his grandfather has inspired Andrew with a love of opera – his rendition of 'O Sole Mio', captured on the Livewire video diaries, is a fully shower-capped performance, complete with spray-nozzle microphone.

Andrew's Internet proficiency is as advanced as the gadgets that surround him. He chats on Livewire, he says, for at least an hour a day, and uses the site to blog about his pets or post occasional photos. His Livewire profile lists 82 friends. Using a regular rather than an adapted keyboard, he's a highly efficient two-finger typist. He spends time on Facebook and MySpace, Skypes with relatives, and is seriously into the online game, Farm Town. If he needs to figure out how to do something – like upgrading Office 2003 to Office 2007, for example – he'll find a tutorial on You-Tube to show him how.

Livewire chat provides Andrew with a social network that his primary school can't. In the special unit he attends, he's one of very few students who can speak, so he's unable to converse with anyone there except the teachers and aides. Through Livewire he is developing networks, friendships and communication skills online, ahead of starting high school next year – where he'll have a lot more opportunities to talk with other young people. But more than a social outlet, the Livewire site extends the many 'enabling' technologies and strategies that Andrew's family encourages in order to help him live life fully.

Andrew's father says that without his computer and other aids, Andrew's activities would be severely limited. Installing a lift at home has meant he can get upstairs or down without help; the intercom lets him banter with his older sister without leaving his room; and the computer and Internet provide a myriad of 'things to do' to replace the physical activities he can't take part in. If he doesn't know how to do something on the Livewire site? He rings them up right away – his family jokes that the Livewire team probably recognize the number and go 'Oh it's Andrew again!', so frequent is his contact.

As researcher Dr Ingrid Richardson says, the way technology is encouraged and accessed in Andrew's home demonstrates more than just a positive approach to his disability: "It's a much broader thing about how to configure and work the environment to enable the body". Andrew's agency as a developing young person both motivates and is strengthened by the range of mechanical and technological 'fixes', and his engagement with sites such as Livewire. "So the enabling technology is one aspect," says Richardson, "but it fits in with a whole range of attitudes about the relation between the body and the world."

Many participants reported that fatigue was a key factor impacting their online engagements. In our study, in simple ergonomic terms most participants stated they used laptops because they could incorporate them into 'rest time', taking them to their beds or the couch, thus simultaneously 'socialise', 'chat', be online and rest (i.e. they could 'fit' the interface into their physical needs). Many of them used the laptop in innovative ways – curling the body around the laptop in bed; resting the laptop on their stomach or chest while they lay horizontal; putting the laptop on the floor and lying on the bed with their head and arms hanging over the edge so they could lie down and type at the same time.
PICTURE: Livewire members using laptops while resting
5.2.3 Livewire Participants’ Use of Online Social Networking

Participant observation visits revealed that, generally speaking, whilst social networking was perceived by Livewire members as fundamental to their wellbeing and their capacity to live full lives, the kind of social networking they undertook did not mirror precisely the kinds characteristically undertaken by others of their generation. Research shows that young people use online social networking spaces to experiment with different identities and social interaction practices. As Katie Donnelly has suggested:

Adolescence is a time for identity construction, and the Internet offers contemporary youth new ways to experiment with identity; including social networking sites, online photo albums and blogs... In doing so, they make use of several new media literacy skills, including judgment, “the ability to evaluate the reliability and credibility of different information sources”, networking, “the ability to search for, synthesise, and disseminate information”, and negotiation, “the ability to travel across diverse communities, discerning and respecting multiple perspectives, and grasping and following alternative norms” (Jenkins, 2006: 4) (Donnelly, 2008: 4).

By contrast, Livewire members tended to be more conservative in their attitudes towards and engagements with social networking interfaces, especially those in the 10 – 15 age bracket. In general, this cohort articulated attitudes that were very closely aligned with their parents’ attitudes towards social networking facilities. While some parents appreciated the benefits of online social networking, many expressed a suspicion of ‘presentational’ media (David Marshall, 2009) – sites that are oriented primarily towards presenting the self for public consumption – which research shows is quite prevalent amongst the adult generation. This attitude translated into a high level of monitoring of Livewire members’ online activities. As a consequence of parental attitudes and practices, a large number of participants reported ‘not liking’ social networking interfaces such as MySpace, Twitter and Facebook, or not ‘seeing the point’. Some expressed concerns about the cybersafety issues popularly associated with these sites. As might be expected of this cohort, Livewire members perceive themselves more ‘at risk’ both physically and socially (particularly as relates to the stigmas associated with disability and/or illness) than their peers. In general, they reported feeling a sense of risk associated with face-to-face communication. This sense of risk translates into the online space. As a result, different parameters shape this cohort’s engagements and experimentations with online social networking spaces. In general, they do not use as wide a range of social networking spaces as their healthy/able peers, with a large majority naming Livewire as their preferred primary online social network. This point of difference from others of their generation relates primarily to the ways safety is perceived by the Livewire cohort and their parents/guardians (See Safety Online below).

<table>
<thead>
<tr>
<th>Existing Research on young people’s use of online social networking</th>
<th>Livewire Research Project Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social networking sites provide young people with an opportunity to experiment with a range of different identities across a variety of diverse contexts.</td>
<td>The kind of social networking undertaken by the Livewire cohort does not mirror precisely that of other young people. Livewire members in general are very safety conscious and are not as ‘experimental’ in online social networking spaces as other young people their age. They do experiment with identity but within more restricted parameters.</td>
</tr>
</tbody>
</table>
5.3 Livewire Participants’ Use of Other Media

Section 5.3 describes Livewire members’ use of a range of both traditional and online and networked media in order to provide a context for understanding the ways they engage with the various components of the Livewire interface.

5.3.1 Television, Books, Magazines and Music

Participants reported watching relatively little broadcast television, preferring to watch DVDs or download movies or television series from the Internet. A number of them expressed negative attitudes towards television. For example, one participant said ‘thank god I don’t watch it as much as I used to’. Those who did watch broadcast television expressed a strong preference for reality television programming.

The majority were avid readers of books and magazines. For a number of them, reading and creative writing was an important part of their identity.

The majority of participants owned an iPod or mp3 player and regularly downloaded/listened to music. Approximately half of those interviewed in Phase 3 reported that they used music ‘therapeutically’ to get them through periods of pain.

5.3.2 Games

Whilst a significant number own games consoles, very few participants played games on a regular basis (with two exceptions who regarded themselves as ‘expert gamers’), and very rarely played multi-player games online. One possible reason for this is that gaming is ergonomically difficult and requires prolonged and dedicated micro-perceptual visual attention and physical dexterity, thus participants with motor function issues, fatigue or physical and/or mental disability may find gaming overly challenging. A number of participants in the chat sessions owned a Nintendo Wii, but commented that they had learnt to play from a seated position using minimalist movements (e.g. flicks of the wrist instead of swinging the arm) rather than a standing position. This illustrates one of the ways in which this cohort invents ‘workarounds’ to accommodate their particular limitations.

Games can be loosely categorised as console games (Xbox, Playstation, GameCube, handheld consoles such as PSP, DS, mobile phone etc), and PC or computer games (both discrete and online), both of which include genres such as First-Person Shooter, Strategy, Adventure, and so on. Research suggests that online multi-player role-playing strategy games such as Neopets, Club Penguin, Runescape, and for more ‘serious’ gamers, EveOnline and World of Warcraft among others (otherwise known as Massively Multiplayer Online Role-Playing games or MMORPGs) provide, increasingly, an important social networking function for young teens (where the text function in the game works similarly to instant messaging or chat). That is, they operate as a ‘third place’ (along with other social networking sites and online spaces such as Second Life) where young people meet to combine both play and social interaction, collaboratively negotiating the virtual world while communicating via text both about the game and other issues. The Livewire participants, however, indicated that when they do play online games, they never utilise them for social networking or chatting.

Only one of the Livewire participants in Phase 3 of the research played MMORPGs, possibly due to the need for hours of dedicated and immersive play in order to succeed in the game (and the ensuing ergonomic discomfort particularly for those who experience fatigue and/or motility and mobility issues), because there is
usually a cost or monthly subscription, and because the multiplayer and often anonymous aspect of game-play was perceived as ‘risky’ both by participants and their parents. This non-engagement with role-playing games signals the potential for Livewire members to become isolated from their healthy peers, or at the very least they do not become adept with the techno-social literacy required to play multiplayer games.

5.3.3 Mobile Phones

Over the past five years there has been a proliferation of research that demonstrates how mobile media devices are becoming increasingly integral to young people in terms of both their communicative and media practices (Horizon Report, 2009). Given that mobile phone use clearly ‘facilitates social inclusion’, enabling peer groups to be in perpetual communication (Walsh et al, 2007), and in light of the emergence of SMS or text-speak as a significant ‘language’ unique to young people, this raises concerns as to whether the lack of mobile phone use and proficiency among Livewire participants is resulting in varying degrees of social marginalisation, isolation or exclusion, poor ‘text-literacy’ and mobile phone skills, impeding their sense of ‘belonging’ to their generation. One participant, for example, stated that she often missed out on information about where her friends were and what they were doing because she didn’t have a mobile phone.

It is also worth noting that mobile phones are no longer simply perceived and used as communicative devices, but have become screen media interfaces in their own right, used for image and video capture, web browsing and uploading user-generated content etc. That is, young people today are becoming sophisticated and literate users of mobile phones as interactive media. Again, if the Livewire cohort are not gaining expertise in this aspect of technological engagement, their mobile media literacy – and media literacy in general – may be compromised.

Phase 2 online surveys and focus group discussions indicated that regular mobile phone use is rare among Livewire participants (with 17% reporting they never use a mobile phone and 39% reporting they use a mobile phone less than once a day). This marks a clear point of distinction from young people’s habitual mobile practices in general. Their limited use is perhaps because mobile phones are considered as both ‘necessary’ for those who are mobile, and a device that in itself facilitates mobility. Thus, because participants are generally more homebound, it appears that a mobile phone is not considered essential by participants and/or their parents. As Gerard Goggin (2006) also notes, in the context of disability, there are various motor function and micro-perceptual issues that inhibit the use of mobile phone technologies.

For those in the Livewire cohort who did own mobile phones (approximately 65% of Phase 3 interviewees), they appear to be a much less entrenched part of their everyday social interactions. That is, they use them less for ‘phatic’ social communication (keeping in touch with friends primarily via texting), and more for voice communication with family (parents, siblings and carers), or as a way to maintain necessary contact while at school or away from home. This reinforces findings from Phase 2 which indicated that Livewire participants are not developing texting skills and text-speak literacy. Research suggests that parents’ primary reason for giving mobile phones to young teens is in order to maintain perpetual contact, that is, the mobile phone works as a constant connection to one’s child, a ‘mum-in-their-pocket’ (Ito, Okabe & Matsuda, 2006). Interestingly, the Livewire participants tended to mirror but invert this attitude; one participant with Cerebral Palsy always carried his phone in a side pocket of his wheelchair, but only used it to call his dad in times of need, an inverse to the usual perception. A number of
participants talked about their mobile phone in terms of the security it provided, enabling them to contact a parent or carer when needed, which is another instance in which this cohort often echoes – more or less seamlessly – parental attitudes towards the technology as a safety device.

### Existing Research on young people’s use of mobile phones and games

| Mobile phones are a key media and communication interface for young people. |
| Livewire members use mobiles to a lesser extent than others of their generation – this raises potential issues of marginalisation, language and literacy.  
When they do use mobile phones, Livewire members tend to text less and voice call more, and often perceive mobiles as a ‘safety device’ – i.e. in utilitarian rather than communicative terms – enabling them to contact parents and carers when necessary. |

| Games – and especially multiplayer online games – provide an important social networking function, a ‘third place’ which integrates play and social interaction for young teens. |
| Livewire members do not play multiplayer games, but do frequently play the casual games on Livewire and integrate this game-play into their sense of community and belonging. |

### 6. Analysis

Alongside the rapid proliferation and uptake of Web 2.0 applications, there has been much speculation about the impact of online communication on young people’s wellbeing. Earlier research indicated that the amount of time young people spent online impacted detrimentally on the quality of young people’s friendships and, thus, on their wellbeing. However, recent research has demonstrated that, rather than hindering young people’s wellbeing, under the right conditions, the Internet can powerfully support and sustain the wellbeing of young people (Oliver, 2006; Gross, 2004; Subrahmanyam, Kraut, Greenfield, & Gross, 2000; Valkenburg & Peter, 2007). Given that young people increasingly use the Internet primarily for interpersonal communication, as Valkenburg notes, “if the Internet influences wellbeing, it will be through its potential to alter the nature of social interaction through the use of online communication technologies” (2007: 1172).

Recent research suggests that the Internet can facilitate a sense of connectedness, community and belonging. Indeed, this sense of community is central to the appeal and popularity of online forums, chat rooms, and virtual spaces (such as Second Life). People generally return to these spaces “because of the experiences they find there, not because of the spaces themselves… The ongoing attraction… is the community – the people that use the space” (Horizon Report, 2009). The sense of community and belonging in turn has the potential to promote young people’s resilience, giving them the ability to successfully adapt to change and stressful
events (Oliver et al, 2006: 1). As Catalano has noted (2002), engaging in meaningful activities, and feeling connected to one’s community are important contributors to the development of resilience (Oliver et al, 2006: 4).

Our findings indicate that Livewire is of key importance to members’ social connection, sense of community and wellbeing. Livewire achieves this by:

- **Chat:** connecting young people living with chronic illness and/or disability so they can share experiences with others who understand their situation
- **Friendships:** encouraging members to reach out to others, have fun and share in a supported environment
- **Safety:** providing a safe space for members’ social interactions, encouraging them to make friends, express themselves and feel supported
- **Embodiment:** providing a space in which members can integrate their sense of identity with their embodiment, allowing them to just ‘be themselves’

This section (Section 6) outlines the key impacts of the Livewire community for members’ wellbeing, drawing attention to the specific ways in which members engage with and experience Livewire. We have highlighted where the analysis of Livewire has provided evidence that expands or contraindicates existing research.

As background, it is important to note that approximately 70% of respondents to the online questionnaire (recruited prior to 31 March 2009) use Livewire more than twice a week (with 40% logging on once a day). This is significantly higher than recent statistics suggest (see graph below), and can partly be explained by the fact that the cohort we surveyed are users who have engaged with Livewire since its inception and thus feel a high degree of loyalty to the community. Nonetheless, it needs to also be noted here that, whether participants engage regularly or not so regularly, they gain a benefit from Livewire. At the very minimum, participants reported that ‘just knowing Livewire is there’ reduces their anxiety because they have somewhere to turn to when they need it most. This is supported by the fact that participants reported spending more time both online and on the Livewire site when they were experiencing personal difficulties – particularly when their illness and/or disability was presenting problems for them. Our research also indicated strongly that the benefits of using Livewire increase with the level of engagement (ie: the greater the access, the more the benefit), however, a focused study into this issue is necessary.

Technology walkthroughs conducted during the interviews indicated that, upon logging on, most Livewire users follow a shared navigation pattern that consists of the following steps:

a) checking emails and messages
b) adding new friends
c) checking the blogs and forums
d) visiting the chat room

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6 “Resilience refers to an individual’s capacity to successfully adapt to change and stressful events in healthy and constructive ways (Catalano, Berglund, Ryan et al., 2002a; Garmezy, 1991). Resilience has been conceptualised as a dynamic process involving an interaction between both risk and protective processes that act to modify the effects of an adverse life event (Rutter, 1985, 1999). In this context, resilience does not so much imply invulnerability to stress, but rather an ability to recover from negative events (Garmezy, 1991)... Building skills that help to promote resilience in young people... is an important strategy in the amelioration of mental health problems” (Oliver et al, 2006).
Approximately 75% of participants say that Livewire is their favourite ‘chat’ site (followed closely by MSN, which they report often having open simultaneously to Livewire). It is noteworthy that participants talk about Livewire primarily as a chat site as opposed to a social networking site. Chat, as a previous report prepared for Livewire found, continues to be the ‘champion’ of the Livewire site (Inside Story, 2008). The Livewire chat interface is atypical in that it requires dedicated screen space (as opposed to MSN which allows messages to appear in one corner of the screen as they arrive). This adds to the sense of Livewire being primarily a chat site.

<table>
<thead>
<tr>
<th>Existing Research on the relationship between young people’s use of the Internet and their wellbeing</th>
<th>Livewire Research Project Findings</th>
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<tbody>
<tr>
<td>Internet usage supports young people’s wellbeing – particularly their communicative and social networking practices and user generation of content.</td>
<td>Livewire is of key importance to members’ social connection, sense of community and wellbeing</td>
</tr>
</tbody>
</table>

### 6.1 Livewire Chat

Previous studies of young people’s online communication have found that, while instant messaging (IM) has a direct impact on young people’s wellbeing, chat does not have any discernible effect. For example, Valkenburg found that “chat... had no effect on adolescents’ well-being” (2007: 1169). However, this observation is based upon the dual assumptions that chat takes place in a public forum and that it is typically used to talk to strangers and form relationships on the basis of shared interests. By contrast, IM is more private – usually involving much smaller groups of participants (often one-to-one communication) – and is primarily used to maintain existing friendship networks (Grinter & Palen, 2004).

In reality, there is considerable overlap between chat and IM modes of communication. Furthermore, at the level of users’ perceptions, the distinction between chat (eg: AOL Instant Messenger) and IM (eg: msn.com) is rarely made. This is reflected in the Livewire cohort’s attitudes towards ‘real-time’ online interpersonal communication. Livewire participants do not differentiate between IM and chat, but refer to both forms of communication simply as ‘chat’.

In technical terms, Livewire operates as a hybrid chat facility that combines characteristics of IM and chat modes of communication. As a closed, moderated online community, Livewire offers a ‘semi-public’ space for young people living with a serious illness, a chronic condition or a disability to meet and get to know strangers, form friendships, and maintain the social networks they establish.
If we consider Livewire as providing a hybrid chat facility, for our participants, it was very clear that Livewire chat fundamentally contributed to their wellbeing. A number of online discussion group participants explicitly said that they ‘looked forward’ to logging on to the Livewire chat room or that it was a ‘highlight’ of their day. Moreover, they reported that the Livewire chat facility provided them with a strong sense of community, as well as a stable and supportive friendship network (See Online/Offline Friendships and Community below), both of which are crucial to a strong sense of wellbeing. During the online focus group discussions, it became obvious that, although Livewire participants have no contact with one another beyond the Livewire chat forums, they knew each other well (signalled, for example, by their intimate knowledge of one another’s lives and the sharing of ‘in-jokes’), shared a strong sense of camaraderie, and had supported one another through challenging circumstances and decision-making processes – they had, as we say, ‘history’.

When participants log on to Livewire, many of them also have other social networking tools active (particularly MSN). However, the Livewire site dominates screen space, and the chat function – particularly now that the chat is busier – requires dedicated attention. As a consequence, users tended to focus primarily on Livewire when they were using the chat facility (and they reported being happy to do so). Research shows that this kind of dedicated attention is rare among users in the age group (Pettersen, 2009; Roberts, Foehr & Rideout, 2005; Tapscott, 2009). In this sense, Livewire successfully commands the attention of users. However, this also raises the question of the level of users’ exposure to other social interactions via alternative interfaces.
The recent increase in the number of users accessing the Livewire chat facility has meant that, for some Livewire members (and in particular those with more limited motility), it is more difficult to keep abreast of the increased pace of the conversations. In particular, they noted that it is difficult to distinguish between ‘whispers’ and the general conversation. A number of members suggested that it might be better if ‘whispers’ popped up in a separate section of the screen.

### Existing Research on young people’s use of online chat

<table>
<thead>
<tr>
<th>Chat doesn’t have any discernible effect on young people’s wellbeing.</th>
<th>Livewire chat is absolutely fundamental to participants’ sense of wellbeing.</th>
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<tbody>
<tr>
<td></td>
<td>Livewire chat is context-specific, distinct from other online chat forums, and indicates a need for the research to work with definitions of chat that are sensitive to context.</td>
</tr>
<tr>
<td></td>
<td>Livewire chat is not only about ‘chat’ – it is an entertainment space in which chat hosts encourage young people to engage in structured games and competitions, providing them with a sense of fun and community.</td>
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</table>

7 In Livewire chat, ‘whispers’ are ‘private’ (but moderated) text-based conversations between two people rather than conversations between the whole group.
8 See footnote 2 for a description of the components of wellbeing.
6.2 Livewire Chat Hosting

Phase 3 interviews with Livewire members indicated that chat hosts are absolutely fundamental to the success of the Livewire community.

The role of Livewire chat hosts constitutes a unique feature of the Livewire ‘chat’ facility. The kind of moderation offered by Livewire is unlike any other chat forum. In the existing literature on chat hosting, ‘moderation’ consists of monitoring interactions to ensure that users’ behaviour accords with relevant chat guidelines, obligations and rules. Livewire certainly performs this kind of moderation, with some participants reporting that they have been suspended for a period of time for failing to follow the rules governing appropriate behaviour. Parents also noted that this kind of moderation was a point of reassurance for them.

One of the most prominent, distinctive features of Livewire that emerged in Phase 3 interviews is that Livewire chat is not only about ‘chat’ – it is an entertainment space in which chat hosts encourage young people to engage in structured games and competitions, providing them with a sense of fun and community. The Livewire chat hosts, as a team, do an excellent job of making members feel welcome, engaging them in conversation, and moving conversation along when it slows down.

The role of the chat host in the Livewire chat rooms varies a lot according to differences in personality of the chat host, but also the kind of young people that log into the space at any given time. In general, chat hosts are much more integrated into the community than in other online chat spaces. According to participants in the Phase 3 interviews, some hosts prefer to stay in the background and allow members to direct the flow of conversation. Others are more directly engaged in guiding the interactions between members and actively participate in conversations and ‘making fun’ with the members. At times the space takes on a kind of ‘theme park’ feel, with Livewire members participating in imaginative group-based outings and activities such as ‘going on an imaginary holiday’, ‘swimming with the dolphins’ or ‘having a food fight’. Further, the presence of the chat host encourages a level of intimacy and dedication from members. This fosters an etiquette that goes beyond the simple monitoring of interactions to ensure that members do not engage in bullying or other forms of antisocial behaviour. Livewire members treat one another as they would treat others in a face-to-face situation. For example, members noted that they don’t just leave in the middle of a conversation but always make sure they say goodbye. This contrasts, for example, with MSN conversation, which tends to be more intermittent, transitory and non-committal.

Because of its unique deployment of the idea of moderation, the analysis of the Livewire site provides a timely intervention into existing scholarly debates about chat hosting and moderation and their impacts on community and youth participation. Existing research on moderation focuses on e-learning, communities of practice, youth participation and cybersafety (both in terms of the risk chat poses and its potential for educating young people about cybersafety) (Donnelly, 2008; Mesch, 2008; Huffaker & Calvert, 2005). Livewire is a unique setting and, as such, further research into its moderation and chat hosting practices will provide new insights into the potential of alternative modes of moderation.9

9 This is one aspect of the research that the research team will look to publish on.
On one level, whilst the centrality of the chat host has, overall, a very positive effect, it is also clear that the role of the chat host needs careful management. Many members noted that, as a stable feature of the community, they looked forward to chatting with the host, and many of them had favourite hosts with whom they had developed a relationship over time. In addition, as chat sessions have become more populated over the last few months, interviewees reported that chat hosts are sometimes the one familiar person in the space when they log on. In this sense, the chat hosts provide a point of continuity across members’ ongoing engagements with Livewire chat. Indeed, many regarded one or more chat hosts as close friends. Some members reported that they used to speak to a particular chat host but ‘now they’re not on anymore’ and that they ‘don’t know what happened to them’. For some this was a source of disappointment. For this reason, it is important that employment turnover of Livewire chat hosts be minimised as much as possible and, when they are necessary (eg: when chat hosts go on holidays or reduce their hours), transitions in and out of the community need to be clearly communicated.

### Existing Research on online chat hosting

<table>
<thead>
<tr>
<th>Livewire Research Project Findings</th>
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<tbody>
<tr>
<td>The chat hosts are fundamental to the success of the Livewire community.</td>
</tr>
<tr>
<td>Chat hosts are active participants and much more integrated into the community than in other online chat spaces, directly engaging in conversations and ‘making fun’ with the members.</td>
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### 6.3 Blogs, Community Forums, Emails, LivewireTV, Livewire Music, Games

Whilst most participants in the third research phase reported that they used the chat facility the most, nonetheless, the overwhelming majority regularly accessed many (if not all) other features of the Livewire site. Their consumption of Livewire TV and downloadable music, as well as their game play, did not follow a predictable pattern. Some accessed these parts of the site frequently. Others only accessed them when they had finished chatting and they went ‘fishing around’ on the site for other things to do, or when they were referred on by a chat host or Livewire friends (ie: to watch a particular funny video or listen to a song etc). This shows that, even though participants may not use the video, games and music as regularly as other aspects of the site, the fact that these things are available and often integrated into chat adds to the sense of community amongst Livewire members. Enabling them to exchange media products with one another fosters a sense of shared cultural knowledge.

Almost half of participants interviewed in the third phase had posted blogs to the Livewire site. Blog topics range from descriptions of outings to talking about pets, from descriptions of hospital visits to commentaries on movies, music and celebrities. Interestingly, when questioned as to why they didn’t write blogs, participants frequently responded that they ‘weren’t good writers’ or ‘didn’t like writing about themselves’. By contrast, those who regularly wrote blogs tended to identify as ‘good writers’. This indicates that there is a perception amongst this
cohort that writing blogs requires special skills/literacies that not everyone is equipped with. Whilst some participants rarely contributed to the blogs, almost all regularly read the blogs, with about half reporting that they frequently commented on others’ blogs. Members cited that being able to read about others’ experiences in this way enhanced their sense of being connected to other members/part of a community. Research shows that this kind of ‘ambient co-presence’ (Ito, 2005) – benevolent visual surveillance of one another – which is typical of social networking sites, contributes to a strong sense of community.

Members regularly check and contribute to the community forums. It is interesting that, in other forums, this kind of facility is commonly referred to as a message board or discussion list but all members referred to them as ‘community forums’ indicating that they have picked up on Livewire’s terminology. The community forums provide an engaging form of entertainment for members, and operate as a space for them to reflect positively on some of the (often humorous) aspects of the experience of being ill or disabled. Again, in doing so, these forums contribute to the sense of community reported by members.

LivewireTV was always talked about in very positive terms. Participants reported especially enjoying videos that featured Livewire members and chat hosts (eg: Livewire Diaries and Chat Host Dares). These texts added to the sense of familiarity with one another, providing members with another point of connection.

In Phase 2, most participants claimed that they did not play games on the Livewire site, regarding them as inferior in terms of graphics and interactivity, reinforcing the view that Livewire is primarily a facility for social networking. However, the third phase of the research revealed some complexities relating to game-play that both reinforced and contradicted findings from Phase 2. Contrary to Phase 2 findings, a number of participants revealed – as they ‘walked us through’ their computer and Livewire use in Phase 3 – that they actively played the casual games on the Livewire site (casual games are stand-alone and of short duration, such as puzzles and word-games, usually without social interaction and non-immersive). Such play was integral to their sense of membership and community, largely due to the frequent challenges posed by chat hosts to members to ‘beat the chat host’s score’. It is often difficult in research to identify the nature of casual game-play, as participants frequently don’t identify casual games as ‘real’ games. For a number of the participants, however, Livewire offered a way for them to integrate play and a sense of community, somewhat similar (though on a smaller scale) to that offered by sites such as Neopets.

6.4 Online/Offline Friendships, Community and Wellbeing

Wellbeing scholarship indicates that the quality of a young person’s friendships is an important predictor of wellbeing (Hartup & Stevens, 1997). For adolescents, quality friendships can buffer individuals from many of the key stressors that characterize the transition from childhood to adulthood (Bukowski, 2001; Hartup, 2000).

The growing prominence of young people’s online interpersonal communication practices in recent years has given rise to a number of concerns – within both public debate and academic scholarship – about the potential for online engagements to draw away from time spent developing and maintaining supportive friendships. In particular, it is feared that the recent and rapid proliferation of mediated communication impacts negatively on young people’s opportunities for face-to-face communication, shifting the locus of individual and community socialisation away from traditional social institutions such as family and school. This is said to leave
young people without an appropriate sense of embeddedness in their community (for a critique of this argument, see Richardson, Third and MacColl, 2007).

However, recent research indicates that the Internet provides an important setting for the maintenance of adolescents’ friendships and their sense of community. Even so, there is a general consensus within the literature on young people’s online social networks that friendships formed online are more ephemeral and ‘weaker’ than offline friendships. One of the problems with this kind of analysis is that it makes a distinction between face-to-face and online communication, whereas recent research indicates that young people do not make this distinction, but flexibly combine a number of modes of techno-social interaction (Richardson, Third and MacColl, 2007).

Further, much research to date indicates that the primary value of online interpersonal communication lies in its ability to support and sustain pre-existing ‘offline’ friendships (Gross, 2004; Subrahmanyam, Kraut, Greenfield, & Gross, 2000; Valkenburg & Peter, 2007). For example, Mark Warschauer has argued that promoting social inclusion using online and networked communities depends upon finding ways of bridging ‘online communication and other means of social networking... Approaches to promoting social inclusion that rely solely on virtual communities are ill-advised... Successful approaches usually combine online and face-to-face networking’ (18, p.162).

6.4.1 Livewire Friendships

Our findings show that the Livewire social networking site successfully mobilises the community building potential of the Internet for its young members living with serious illness, a chronic condition and/or disability, and that Livewire friendships are crucial to members’ wellbeing. Moreover, the analysis of Livewire friendships challenges key assumptions about the quality and strength of online friendships on several fronts.

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<thead>
<tr>
<th>Existing Research on young people’s friendships and their wellbeing</th>
<th>Livewire Research Project Findings</th>
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<tr>
<td>Strong friendships are an indicator of wellbeing.</td>
<td>Livewire friendships are central to members’ wellbeing.</td>
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The overwhelming majority of Livewire participants view online friendships – and in particular their Livewire friendships – as the most important, dependable and enduring friendships they have. In some cases, the other members of the Livewire community are the only friends with whom they have regular contact. Livewire thus offers a crucial space in which this cohort can interact with others their own age.
Case Study: Jess
Building friendships and identity through Livewire

At 13, Jess was loving ‘teenagedom’ – getting high grades at school, hanging out with a big group of friends, and always active. It looked like the best years of her life were unfolding – all the freedom and excitement of adolescence was coming her way and she was ready to grab it with both hands. Then one day in early 2006, she woke up and couldn’t walk.

It was the beginning of months of uncertainty and terrible pain. After countless tests she was diagnosed with Myalgic Encephalomyelitis (ME) and Fibromyalgia – conditions that contribute to wasting of muscles and bones, a compromised immune system and frequent infections, severe fatigue and regular blackouts.

Now 17 and coming to terms with her illness, the vivacious Jess is crazy about fashion, cricket, fighter jets and the Essendon AFL team (the ‘Bombers’ – maybe there’s a link?). Her bedroom is decorated in team colours from top to bottom. Though she comes from “an Essendon family”, her particular obsession began when two of the players heard she was a supporter and visited her in hospital.

During two years of severe deterioration, Jess was unable to do basic things like walk or feed herself; she also lost all but one of her friends, her high school life, and her identity as ‘Jess’ – she says she instead became ‘the sick girl’, and upon returning to school was subjected to taunts and bullying. She first joined Livewire while in rehab, learning to walk, feed herself and use her hands again. Initially she read the articles, blogs and features, and eventually tried out the chat room.

“What I loved most about Livewire was the fact that everyone was a teenager with a serious illness or a disability,” she says. “We were simply all the same. And for the first time in years I was ‘normal’.”

Jess’s use of the site highlights the value of Livewire for young people needing to rebuild or consolidate their identity while dealing with serious illness or disability. Her experience is not uncommon, says researcher, Dr Amanda Third.

“Our research showed how important the participants were to one another,” Dr Third says, “and how integral the site was to their sense of identity as they grow through adolescence; how that community is really important to fostering a healthy sense of identity.”

Jess agrees that the participants are the most important element of Livewire for her – she is on the site every day now, and enjoys close friendships with other site members.

“People don’t understand how you can become friends with someone you have never met,” she says. “But when you have shared so many highs and lows together the fact you have never met in person is irrelevant.”

“In that moment when we are all laughing, chatting and joking together, nothing else matters. The fact that perhaps we are stuck in bed, our hair is falling out or machines are breathing for us is completely irrelevant. In that moment we are teenagers laughing. And that is all that matters.”

When Jess is too sick or in too much pain to chat on Livewire, she maintains her social networks through mobile SMS, plays iPod games to distract herself “until the painkillers kick in or until I pass out”, or dreams of the next time she might get to an Essendon game. Her favourite player is Angus Monfries, but unfortunately he wasn’t one of the players who visited her in hospital. “I wish!” she says. “I told Mum and Dad I reckon if I met him I’d go into remission!”
As noted above, participants tend to spend more time both online and on the Livewire site when they are confronting difficulties, particularly those related to their illness and/or disability. They spoke in glowing terms about how their Livewire friendships supported them through difficult times. For example, one young woman reported that she turned down a medical procedure offered to her in hospital. However, when she reported this to the other Livewire members in a chat session, they talked her through the reasons for her decision and helped her realise that it would be a good thing for her to do. This example and others indicate that Livewire is a space in which these young people make important life decisions in a supported manner. Far from considering online communication as a ‘poor second’, this cohort have an acute sense of the possibilities and practicalities of online communication.

Livewire members reported finding it easier to make friends online than offline. This goes to the heart of how Livewire members understand friendships. ‘True’ friendship is defined by this cohort in terms of how people react or relate to their condition or disability – true friends are ones that accept their condition or disability.

Against the grain of the argument that online communities work best when they are integrated with offline, Livewire deliberately cleaves the online from the offline in order to provide a sense of safety for participants. In the online research phase (Phase 2), some participants expressed frustration with the fact that they are not able to contact each other offline by, for example, exchanging personal information such as phone numbers or pointing other participants to their profiles on other social networking sites. However, this clearly does not undermine the strength of, or value ascribed to, the friendships participants nurture in the Livewire setting. Indeed, for reasons specific to the Livewire cohort that we elaborate in more detail below (see Embodiment, Identity and Empowerment), this appears to strengthen friendship ties amongst the Livewire community. In Phase 3 of the research, the researchers followed up these observations with a series of questions about how the Livewire privacy policy impacted on members’ interactions and the strength of their friendships. Findings generally supported our initial understanding. However, a number of related issues emerged. One quarter of participants said that they were very content to have contact with the Livewire friends via the Livewire community only. Just over a third of the participants said that they would appreciate the opportunity to meet all their Livewire friends face-to-face or have contact with them via other forums such as MSN. The remaining participants said they would take the opportunity if it arose but they would not actively seek it. Approximately one third of participants had taken advantage of Livewire’s policy of facilitating other forms of contact with appropriate permission from members’ parents. However, approximately half were not aware that they were able to do this. Overall, members accepted the Livewire terms and conditions pertaining to privacy as a stipulation of their participation. However, a number of members noted that they had experienced periods of anxiety when Livewire friends had ‘disappeared’ from the site to have surgery or other medical treatments. One participant in particular said that she and a number of others on the site had panicked when one of their Livewire friends had not returned to the site for quite some time after he had undergone life threatening surgery, and feared that he had passed away. Clearly mortality is an issue that arises in this kind of forum. Members who raised this concern said that it would be helpful if Livewire could facilitate some kind of communication in such circumstances.
Existing research demonstrates that helping others can enhance young people’s sense of resilience (Oliver, 2006). Livewire participants reported enjoying a strong sense of satisfaction at being able to help others in a similar situation. During Phase 3 interviews, this was a common theme. In particular, using Livewire as a basis for positively identifying with her illness, one participant had gone on to become an advocate for raising awareness about her condition, receiving a prestigious award for her efforts.

Not surprisingly, in Phase 3, it became obvious that members were very dependent not only on Livewire friendships but also on family structures (both nuclear and extended) for ongoing support. Many of the interviewees expressed that they considered themselves different from other young people. They gave reasons for this that ranged from physical differences to differences in maturity and ‘worldview’. Whilst it is tempting to suggest that one of the reasons Livewire members relate to other members is due to greater levels of maturity (arising from having faced the challenging life experiences of living with chronic illness and/or disability), several members were keen to point out that Livewire provided them with a space in which to ‘just be a kid like other kids’. Livewire appears to balance members’ need to ‘be a normal kid’ with their need to interact with other young people who can relate to their circumstances.

This helps to explain why, even when members recover from an illness, they continue to visit the Livewire site – albeit to varying degrees (ranging from daily to ‘every now and then’). Interviewees reported that there were two key factors impacting on their desire to continue to engage: On the one hand, they had formed strong friendships they wanted to maintain, and on the other, they said that Livewire provided them with a space in which to engage with other people with a similar outlook on the world (the implication being that their friends outside the Livewire site didn’t always have the same understanding of the world).

Our questioning around members’ sense of difference from other young people revealed an interesting paradox. For many, the need to embrace their difference was a necessary part of coming to terms with their illness and/or disability. A majority of participants reported having been subject to various forms of bullying both online and offline, accentuating this sense of difference. In this sense, Livewire provided them with a ‘safe’ community of solidarity formed around the idea of being different to other young people that enabled them to cope with some of the difficulties associated with being chronically ill or disabled (our participants cited bullying, losing former friends, not being able to attend school, having limited social outings and opportunities etc as problems they faced). It was clear that the ‘protected’ space of Livewire was fundamental both to their wellbeing and their capacity to develop the necessary skills to engage in social settings external to Livewire. However, in interviews with a small number of participants, it became obvious that there is a fine line between, on the one hand, encouraging participants’ sense of mastery and control and supporting their independence and, on the other, fostering a dependency on Livewire to fulfill a member’s complete social and interactional needs. That is, there is a ‘tipping point’ at which the positive impacts of members’ engagements transform into an overdependence on the technology and the Livewire community to deliver a total social world. The factors impacting on this dynamic would be worth researching in further detail.
Case Study: Leah*
Being different and feeling ‘connected’

Leah is barefoot on the day of her interview, her blonde hair tied back in a firm ponytail. She wears a ‘Braves’ sweater and jeans; one arm hangs loose over her lap and the other is crossed, holding her elbow. She’s one of the original Livewire users, having been invited to join a pilot group for the site about eighteen months ago. Born with a serious immunodeficiency, and having experienced almost constant illness and countless treatments for most of her 14 years, she understands keenly what it means to be different.

Not only do words like ‘hypogammaglobulinemia’ and ‘bronchiolitis’ roll lightly off Leah’s tongue (her grasp of medical Latin is phenomenal); her detailed understanding of procedures, treatment regimes and surgery is far beyond that of the average adult. Despite frequent infections and hospitalisations she has recently skipped a high school year, moving straight from Year 8 to Year 10. But school is not her great love – it’s sport that gets her going. She plays basketball, netball, swims, you name it – even three knee operations hasn’t stopped her.

For Leah, Livewire provides a crucial and unique point of connection with other kids her age. She says that on Livewire she can talk about things that “normal kids” don’t understand – “surgery, procedures we’ve had, near-death experiences, stuff like that”.

“A lot of people would sit there, put their fingers in their ears, close their eyes and rock,” she says. “It’s just harder to say what we say on Livewire to other kids that haven’t been through it. They just don’t get it.”

Leah finds that at school, it’s best not to give too much detail.

“I’m not exactly forthcoming with information: like [they’ve asked] ‘You were away, where were you?’ ‘Oh, I had the flu’. I didn’t tell them I’d been away in Sydney seeing specialists about another surgery. It’s just the way it is really. Kids are very harsh”.

Researcher Dr Ingrid Richardson notes the distinction between the online environment of Livewire, and the ‘real world’. “With face-to-face they get the stigma, they get the people who don’t get it,” she says, “whereas in the Livewire world they’re accepted and everyone understands.”

While Livewire offers valuable ‘safe space’ for kids living with chronic illness or disability, it could, says Dr Richardson, potentially also operate as a ‘shield’, so that some members might avoid developing robust relationships with their ‘normal’ peers.

“This is one context where you can simultaneously have two things going on at the same time, that actually seem at cross purposes but in fact are not,” Dr Richardson says.

“So Livewire provides a kind of cocoon, in a sense, in which Leah can be herself; and though that would seem to make it more difficult to involve herself in the ‘real world’, in actual fact she’s highly active and engaged.”

When she’s not at school, in hospital, at the pool or on the basketball court, Leah hangs out with her family – including two enthusiastic dogs – as well as helping care for sick and injured wildlife. In her bedroom is a huge plastic crate containing a pink blanket and three fully feathered but flightless galah chicks. She touches a finger to one beak and the chick squawks loudly. Apparently a blend of hen-rearing mix, egg and biscuit is the appropriate treatment.

* For privacy reasons, this member’s name has been changed.
### Existing Research on young people’s online friendships

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<tr>
<th>Existing Research on young people’s online friendships</th>
<th>Livewire Research Project Findings</th>
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<tr>
<td>Online friendships are weaker than offline friendships.</td>
<td>For Livewire members online friends are viewed as ‘true friends’, defined as those who accept their chronic illness and/or disability.</td>
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<tr>
<td>Online friendships are most successful when they are integrated with and support offline friendships.</td>
<td>For Livewire members, online friends are often viewed as more dependable and enduring than offline friends.</td>
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<td>Livewire is a space where members make important life decisions through chat conversations with their peers. eg: whether to undergo difficult treatment or procedures.</td>
<td>Livewire friendships balance members’ need to ‘be a normal kid’ with their need to interact with other young people who can relate to their circumstances.</td>
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<tr>
<td>Livewire friendships balance members’ need to ‘be a normal kid’ with their need to interact with other young people who can relate to their circumstances.</td>
<td>The strength of Livewire friendships is evidenced by members’ continuation of their engagement with Livewire post-recovery.</td>
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<tr>
<td>Helping others enhances one’s sense of resilience.</td>
<td>Livewire members gain a sense of resilience through helping others in the Livewire space.</td>
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### 6.5 Safety online

Both popular and academic discussions of young people’s online and networked communication have been dominated by the cybersafety debate, which tends to focus on issues surrounding anonymous bullying, predation, flaming and identity theft. In the case of the Livewire online community, the existing interpretive framework provided by the cybersafety literature is not an appropriate ‘fit’ for several reasons. Firstly, Livewire is a closed (password-protected) and moderated site, minimizing conventional cybersafety concerns. Livewire thus affords its participants with a secure online environment in which each member is identifiable and authenticated by the Livewire team. A Livewire moderator is always present in the chat rooms, so problems such as bullying are closely monitored and addressed.10

Secondly, Livewire participants indicated that they were not concerned with traditional forms of ‘risk’ as they are identified in the cybersafety literature.

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10 To clarify, moderators sometimes leave the chat room to take a break for lunch etc. However, if they do so, they alert the members in the chat room. When the chat host returns to the computer, they review the chat transcripts to ensure that the members have been abiding by the guidelines on appropriate conduct.
Significantly, however, the issue of 'safety' was still of some importance, albeit in a different form. In the online focus group discussions a number of participants stated that the Livewire chat forums provided a 'safe' space, with 'safety' more subtly defined as freedom from marginalization and subtle forms of prejudice (as opposed to explicit bullying) based on their illness and/or disability. This allowed them to 'be themselves'; to openly communicate to empathic others who understand if they are feeling sick, tired, angry or afraid. Their notion of safety thus relates directly to their sense of embodiment and identity.

Case Study: George*
A more nuanced view of safety

George loves games – online games, PlayStation, Wii, DS, as well as whatever he has on his mobile phone, and whatever he finds on Livewire. He plays Trackmania online and chats with other competitors at the same time; he plays games with his brother, friends, his girlfriend, or alone. At nearly 19, he’s looking forward to enrolling at TAFE and pursuing an IT career. Meanwhile, when he’s not gaming, he’s chatting on Livewire or heading out for a walk with his mother and his older brother – both young men have the same disability and use wheelchairs. He’s also recently started flying remote-control planes – his current model, a classy e-glider the size of an albatross, is, he says, both a great flyer and sturdy when it comes to the occasional crash.

George’s mother Regina wants to know George is safe whatever he’s doing, and sees Livewire as a particularly 'safe space' that gives him “a bit of everything”. Like many parents of young adults with chronic illness or disability, she’s especially risk-aware, seeing first-hand some of the vulnerabilities such kids experience.

George also has concerns about ‘cybersafety’, and likes Livewire in part because he knows those he meets there are genuine. “You know not to trust people [on the Internet],” he says, “but on there I know I can. I’m safe.” He also has a filter installed in his web browser, which monitors web content by colour codes: “If it’s red it’s bad, if it’s yellow it’s OK, if it’s green it’s good,” he says.

For many Livewire users, including George, ‘safety’ also means freedom from bullying, teasing and prejudice. On Livewire, George says, social interaction is straightforward; he can dip in and out of it, and it’s relatively easy to make friends.

“It’s good to meet other people with a disability – on other sites I haven’t made that many friends. They all have different things to put up with [on Livewire]. They’re more understanding.”

Researcher Dr Ingrid Richardson says that the Livewire space is very important to members’ sense of being a normal adolescent. “A number of kids we spoke to talked about the fact that Livewire was the only space where they were really themselves.”

In George’s case, ‘safety’ implies being able to relax online with friends who understand his situation – though he cites virus-laden downloads as another serious issue that Livewire circumvents for him. He enjoys other friendships through and via gaming environments – and understands the risks associated with them – but Livewire continues to be a site that he can revisit with a sense of security. As a person whose daily life will always involve dealing with considerable challenges, this ease of interaction can’t be underestimated.

* For privacy reasons, this member’s name has been changed.

This more nuanced and specific sense of safety online indicates a clear point of difference from the cybersafety needs of young people more generally, such that for this cohort, we need to re-contextualise the cybersafety issue within broader notions of wellbeing and resilience. Clearly, the members who join and participate regularly on Livewire chat forums prioritise this more nuanced sense of safety, which is provided by both the close moderation and the membership itself (a community that ‘understands’). This said, it is not clear to what extent these factors may also act a deterrent for other young people living with chronic illness and/or disability – particularly those in their mid-to-late teens – who prefer more open and unrestricted online communication (such as MSN), or who are disinclined to engage with an online community that is defined by illness and disability (i.e. where membership is exclusive to young people living with a serious illness, chronic health condition or disability).
In the third phase of our research, the home-visits provided us with an opportunity to chat with Livewire participants about the safe space that Livewire provides, and to gain some insight into both the participants’ and their parents’ attitudes towards online safety and risk. As suggested above, although the Livewire participants tended to view safety in a unique manner, parents viewed online safety in more conventional terms (as protection from predation and bullying etc); many parents, for example, had installed a ‘net nanny’ or equivalent filtering software on their children’s computers, and the computer was more often than not situated in the family or common room to allow for constant visibility. It was clear that the parents of these young people were very concerned about the dangers posed by online communication and social networking, and viewed Livewire as a place of interaction that required no overt supervision; that is, unlike other web services such as Facebook and MSN, Livewire offered a space cocooned off from the perceived risk of open and unmoderated online engagement.

As noted previously, Livewire is fundamental to this cohort’s ability to develop meaningful and supportive friendships, yet this raises an interesting paradox of connection and disconnection. At times, the participants’ sense of belonging and connection to the Livewire community also worked to accentuate their ‘difference’ from other young people, while the nuanced sense of safety provided by Livewire was clearly distinct from the risks of both online services outside Livewire and face-to-face interaction in the ‘real world’ experienced by young people more generally. A number of the Livewire participants in their mid-to-late teens thus spoke of a necessary process of transition, which involved a gradual lessening of Livewire time, and an increase in time spent with offline friends who also ‘understood’ (yet who, in most cases, did not have a chronic illness and/or disability). Whether Livewire members choose to ‘move on’ from Livewire or remain engaged with the community in a mentoring capacity as they grow older, Livewire provides an important function in this process of transition, enabling members to develop a positive sense of identity as they move from a state of identifying with their chronic illness and/or disability to becoming young adults in-the-real-world.

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<th><strong>Existing Research on young people’s online safety</strong></th>
<th><strong>Livewire Research Project Findings</strong></th>
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<tr>
<td>Cybersafety dominates discussions of young people’s online engagement. In these contexts ‘safety’ is defined in terms of protection from bullying and online ‘predators’.</td>
<td>Livewire members prioritise safety, but define safety as freedom from prejudice and marginalisation on the basis of their illness and/or disability. The issue of safety for Livewire members thus relates directly to issues of identity and embodiment. Understanding safety in the Livewire context requires broader notions of wellbeing and nuanced concepts of safety. Livewire provides an important function in the process of ‘transition’ for some members – the shift from identifying with chronic illness and disability to becoming young adults in the ‘real world’.</td>
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Livewire is not forever: eventually increasing study commitments, a return to health, or just ‘growing up’ mean less time or fewer reasons to visit the site. But the experiences, friendships and personal skills gained in the Livewire environment are not left behind. Annie’s story shows how Livewire can play a significant role in coming to terms with illness or disability, connecting with others in similar situations, and moving towards a more empowered sense of self.

Annie is 16 and has juvenile arthritis; already as a young adult, she’s an active advocate for Livewire, the Starlight Children’s Foundation and Arthritis Australia. But she hasn’t always had the self-acceptance and motivation to help others that she has now. Since the onset of the disease at age eight, she’s been through significant periods of emotional distress, rebellion and denial – experiences she’s been able to share, process and move on from, in part through her engagement with the Livewire site.

Annie says that when she was first diagnosed, she couldn’t grasp what was happening to her, and doctors were unable to explain it to her in language she understood. “I was in pain but I didn’t know why,” she says. She joined Livewire when she was around 13; some of the intervening years were difficult. Annie’s mother describes how her ‘good girl’ became angry and rebellious, and she realised her daughter was not dealing emotionally with the illness.

“Annie went through a grieving period,” she says, "where all of a sudden she realised she had to come to terms with the fact that the life she had was no longer... It was really hard to see a future for herself.”

Annie was logging into Livewire regularly when she first joined. "I needed it a lot,” she says. “There’s no other place where we can release those feelings.”

“I could listen to other people’s stories and compare our lives. And there were people who had harder lives than me and there were people who were just starting off with the disease, and I could tell them hints and points about things. No one had juvenile arthritis, but there were things that were similar.”

Researcher, Dr Amanda Third, sees Annie’s engagement with Livewire as a passage from the initial realisation of illness to a process of reconciliation and eventual acceptance.

“For some participants, having the Livewire space for interaction and development of friendships, and for working through the issues they have, is absolutely vital to them being able to move on from that context in order to cope in the real world as a person with a serious illness or disability,” Dr Third says.

Annie, now in Year 10 and very busy with school assignments, only gets onto Livewire about once a week nowadays, and has little time to enjoy the chat, in particular. But her experience of the site has a direct relationship, she says, with the advocacy work she now does.

“That’s what I do with Livewire – I talk a lot. So with my advocacy work, I do a lot of talking – for Livewire, the Starlight Children’s Foundation and for Arthritis Australia. Because I have something, and it’s horrible, but I want to make something good out of it.”
Much of the discussion surrounding young people’s online communication also concerns the dangers of excessive computer and web use for health and wellbeing, and the need to balance computer time with face-to-face communication and physical activity with others their own age. Yet for many of the Livewire members, particularly those suffering from severe disability and/or chronic illnesses, most of their communication and ‘socialising’ takes place online, and is at times the only means available to connect with others of their generation. Several of the participants, for example, reported that they ‘had no friends’ outside of Livewire, as they were frequently homebound, in hospital, and unable to attend school. Several of those who did attend school commented in both the online surveys and chat sessions that in the school environment they were often subject to bullying and teasing – that it was an ‘unsafe’ space – and so preferred the emotional safety of being online. In this context, we would argue, the existing research and interpretive frameworks surrounding the benefits and risks of online engagement, and its impact on the safety, wellbeing and resilience of young people, needs to be critically re-examined for its applicability to young people living with a serious illness, chronic health condition or disability.

6.6 Embodiment, Identity and Empowerment

In much of the popular and academic literature surrounding the enablements of online communication and cyberspace more generally, there is often an underlying assumption that being online allows us to ‘leave the body behind’, free to construct ideal or imaginary identities not tied to our material or physical existence. Contrarily, face-to-face or even voice-based communication inescapably tethers us to our physical embodiment. In disability studies it is often assumed that people who experience physical impairment or the visual ‘stigma’ of disability desire such an escape from the body more than so-called ‘normal’ people. As Lupton et al note, while the ‘normal’ body has a “typically ‘absent’ status…the body of the physically disabled person is constantly ‘present’” (Lupton, 2000: 1857). Here, the body represents a ‘problem’, and online communication offers a (temporary) solution, affording those living with disability the capacity to experience an ‘absent’ body and ideal self. In their paper ‘The Disability Divide in Internet Access and Use’, Dobransky and Hargittai (2006: 316) state:

The most striking aspect of online communication for people with disabilities is the ability it affords the user to hide aspects of him- or herself. For people with disabilities, online communication may allow the removal of their disability from the forefront of interaction…Unlike communication in the offline world, where the stigma of disability or one’s impairment itself may at times prevent one from venturing into the world freely and interacting with others, online communication allows the individual with disability to encounter and interact with others to a degree that may not be possible offline (Seymour & Lupton 2004; Guo et al. 2005).

In our analysis of the Livewire cohort, however, this interpretation is overly simplistic and generalised, and does not effectively capture the complex way in which the participants experience their embodiment and identity in the Livewire chat forums. For the Livewire members who participated in the online focus group discussions (12 participants across four sessions), aspects of their ‘embodiment’ were present in the discussion in quite pragmatic and matter-of-fact ways. e.g. participants freely talked about how their illness and/or disability prevented them from doing ‘normal’ things such as going out or attending school, about their medication and its effects, and in expressing their views on online friendship, participants referred to previous chat discussions with their Livewire friends about...
upcoming procedures and other issues concerning their condition. Thus it was apparent that, in the context of Livewire, there was no desire or need for members to disaggregate their embodiment and identity – to render the body ‘absent’. This is perhaps because for the Livewire participants, in the unique chat environment Livewire provides, their illness and disability could be ‘present’ but not ‘focal’ or defining, engendering a sense of normalcy and allowing for a more full-bodied representation of their ‘self’ to other members.

Thus while the Livewire participants expressed having difficulties talking about their embodiment with their offline friends – whether that be aspects of their chronic illness and/or disability, or mundane issues concerning their bodies or physical appearance which nevertheless foregrounded their difference – in the Livewire space they could ’be themselves’ in a way usually ascribed to more in-depth, offline, face-to-face relationships. We would argue that the density of their Livewire friendships – in comparison to both other offline and online friendships – is at least partially due to the way they are enabled to positively reintegrate their embodiment and identity in this online environment.

In Phase 3, it was observed that, whilst Livewire participants expressed a high level of comfort in relation to discussing their illnesses in physical terms, they did not necessarily experience this same degree of confidence in talking about illnesses they perceived as ‘mental illnesses’. Two female respondents, both with eating disorders, confessed that they did not disclose this information on the Livewire site. One declined to give any information about her illness (either in the Livewire space or in the participation observation interview conducted by the researchers). The other respondent has a series of health issues, her eating disorder being the most recently diagnosed. She said she talked openly and freely about her other conditions on Livewire but had not shared her eating disorder with any of her Livewire friends. When questioned about this, she said that she didn’t feel comfortable disclosing any ‘psychological’ conditions. Thus while Livewire provides a ‘safe’ space for members to talk about many chronic conditions, serious illnesses and disabilities, the Livewire team might give some further thought to how to reduce stigma and support those living with conditions that are culturally defined as ‘mental illness’.

The participant observation home visits carried out in Phase 3 enabled us to observe the participants use of technology in the ‘contexture’ of the material constraints and enablements of their domestic space, and the way this related to their sense of agency and self-determination. It was clear that perceptions of ‘ableness’ – of what participants could and couldn’t do as a result of their illness and/or disability – was often less to do with their actual physical condition and more a product of social and familial attitudes towards the condition, and the way that the house was configured as a space of empowerment and enablement.

One participant was intermittently wheel-chair bound according to the severity of her condition (at various times unable to walk and only able to stand for twenty or thirty seconds at a time). Within the house, which was a small rental property, the wheelchair was at times difficult to manoeuvre and tacitly regarded as a bit of a nuisance; the participant showed us how she would sometimes drop to her knees in order to get to the phone ‘before her sister’, the foot supports had been removed from the chair to allow easy turning in the hallways and bedrooms, and it could only just squeeze between the kitchen counter and refrigerator, making it difficult to enter the kitchen. The wheelchair also did not fit properly under the dining room table where the computer was most often situated – the participant perched on the end of the chair (while putting no weight on her ankles) as she showed us how she used Livewire. Thus the participant either created innovative ‘workarounds’ or was materially constrained within the parameters of the built environment. Another
participant, in contrast, used his state-of-the-art wheelchair to its full functionality, in a house with doorways re-designed for manoeuvrability, and a ‘control station’ in his bedroom complete with computer, wireless broadband, iPod, stereo speakers, and cordless phone. Yet there were still workarounds needed – the most significant and complex, perhaps, was learning how to use the computer keyboard and mobile phone pad with accuracy. This facilitating/non-facilitating dynamic was present to greater or lesser extents at most of the participants’ houses, and was dependent on several factors: house ownership (and/or availability of funds for renovation and new technologies), attitudes towards and perceptions about the illness, chronic condition or disability (e.g. whether it was perceived as temporary or permanent), and a reflection of attitudes about technology as a powerful ‘enabler’.

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<td>Chronically ill and disabled people seek to ‘hide’ their embodiment online.</td>
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Research suggests that for young people a sense of empowerment and accomplishment in online environments – which is often integral to an increased sense of belonging and attachment to a particular community – is further enhanced when users have at least partial ‘ownership’ of the online space, or when they themselves contribute to the design and are able to upload user-generated content. i.e. when they help to co-create the online communal space to which they belong. As we have suggested, there are clear benefits to the moderated nature of the Livewire site, yet we would nevertheless suggest that a more user-led approach, such that members have more opportunities for customisation and content creation, would further enhance members’ Livewire experience. In addition, we would ask if there is potentially a balance can be achieved – particularly for older members – between the current closed and discrete nature of the Livewire site and the open, hyperlinked, networked and sometimes ‘risky’ plethora of current Web 2.0 services and applications such as MySpace, Twitter and Facebook.
### Existing Research on the Internet and young people’s mastery and agency

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One final observation from Phase 3 relates to the gender, racial and socio-economic bias in terms of membership. i.e. the overwhelming majority of the participants we interviewed were female, Caucasian, and residing in middle-to-upper class suburbs. Research suggests that social networking is an activity girls are more inclined to engage in (Turkle, 1998; Turkle, 2005), and that girls are more likely to use media and computer technologies for communicative purposes, whereas boys are more utilitarian in their technology use. The gender bias of Livewire members reflects this trend. In terms of racial and socio-economic factors, Livewire might consider how to extend their service to socio-economically disadvantaged and indigenous young people living with chronic illness and/or disability.
7. Future Research

This report has outlined Livewire’s successes. It has also signalled a range of challenges facing Livewire into the future, as the community continues to grow. The following suggest possible avenues for future research into the Livewire community.

1.1 Approximately 50% of members who recover from illness continue to use Livewire post-recovery because they have formed strong friendships they want to maintain. It is also clear that whilst some participants (post-recovery or otherwise) only access Livewire occasionally, it is still an important forum for them, and one that they turn to in times of difficulty. It thus appears Livewire has relatively low attrition rates. However, this study primarily interviewed Livewire members who have been in the community since it was first piloted, and thus, feel a strong degree of loyalty. As such, it is difficult to draw conclusions about issues of attrition. A longitudinal study is required to answer these questions. It is recommended that Livewire undertake a longitudinal study of member engagement to better understand the issues shaping attrition.

1.2 Our interviews indicated that regular contact is not necessary for a member to feel like a part of the community, to reap the positive benefits of Livewire, or to see a need for Livewire in their lives. However, a longitudinal study of members’ modes of engagement would reveal the complexities shaping the level of engagement/benefit ratio.

1.3 Livewire mobilises chat hosting and moderation in a highly unique and productive manner to construct and sustain a strong community of support for young people living with chronic illness and/or disability. There is currently a limited evidence-based scholarship addressing the potential of chat hosting and moderation for community building amongst adolescents. The insights drawn from the analysis of the Livewire community have much to contribute to scholarship internationally. It is thus recommended that Livewire pursue opportunities to publish on and promote the Livewire model of chat hosting and moderation in both services and research sectors.

1.4 Livewire supports young people living with a chronic illness and/or disability to develop friendships, life skills, a sense of mastery and control, and independence – all of which are crucial to adolescent development. However, precisely because Livewire is so effective, there is the potential for this cohort to overdepend on a service like Livewire to deliver a total social world. This report recommends that Livewire pursue further research into the factors impacting the independence/overdependence dynamic in order to understand better the limits of members’ healthy engagement with Livewire.

1.5 In the process of conducting this research, it became evident that there is a range of transition issues that confront Livewire members as they grow up or recover. This report thus recommends a study of transition issues impacting Livewire membership and engagement.
8. Summary of Findings

Centre for Everyday Life – Murdoch University  
Dr Amanda Third and Dr Ingrid Richardson

**Project Title:** 
Livewire Research Project: Final Report

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<td>The Internet plays an increasingly central role in young people’s lives globally. Young people use the Internet primarily for interpersonal communication.</td>
<td>Internet usage is of particular importance and pertinence to the Livewire members. Livewire participants use the Internet primarily for interpersonal communication. Online communication provides Livewire participants with a reliable point of social connection when their lives are disrupted by periods in hospital or at home, or when mobility is an issue.</td>
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<td>Social networking sites provide young people with an opportunity to experiment with a range of different identities across a variety of diverse contexts.</td>
<td>The kind of social networking undertaken by the Livewire cohort does not mirror precisely that of other young people. Livewire members in general are very safety conscious and are not as ‘experimental’ in online social networking spaces as other young people their age. They do experiment with identity but within more restricted parameters.</td>
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<td>Mobile phones are a key media and communication interface for young people.</td>
<td>Livewire members use mobiles to a lesser extent than others of their generation – this raises potential issues of marginalisation, language and literacy. When they do use mobile phones, Livewire members tend to text less and voice call more, and often perceive mobiles as a ‘safety device’ – i.e. in utilitarian rather than communicative terms – enabling them to contact parents and carers when necessary.</td>
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<td>Games – and especially multiplayer online games – provide an important social networking function, a ‘third place’ which integrates play and social interaction for young teens.</td>
<td>Livewire members do not play multiplayer games, but do frequently play the casual games on Livewire and integrate this game-play into their sense of community and belonging.</td>
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<td>Internet usage supports young people’s wellbeing – particularly their communicative and social networking practices and user generation of content.</td>
<td>Livewire is of key importance to members’ social connection, sense of community and wellbeing</td>
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<td>Chat doesn’t have any discernible effect on young people’s wellbeing.</td>
<td>Livewire chat is absolutely fundamental to participants’ sense of wellbeing. Livewire chat is context-specific, distinct from other online chat forums, and indicates a need for the research to work with definitions of chat that are sensitive to context. Livewire chat is much more than ‘chat’ – it is an entertainment space in which chat hosts encourage young people to engage in structured games and competitions, providing them with a sense of fun and community.</td>
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<td>Moderation and chat hosting monitor interactions in order to ensure that users abide by guidelines and rules governing chat interactions.</td>
<td>The chat hosts are fundamental to the success of the Livewire community. Chat hosts are active participants and much more integrated into the community than in other online chat spaces, directly engaging in conversations and ‘making fun’ with the members.</td>
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<td>Online friendships are weaker than offline friendships. Online friendships are most successful when they are integrated with and support offline friendships.</td>
<td>For Livewire members online friends are viewed as ‘true friends’, defined as those who accept their chronic illness and/or disability. For Livewire members, online friends are often viewed as more dependable and enduring than offline friends. Livewire is a space where members make important life decisions through chat conversations with their peers. eg: whether to undergo difficult treatment or procedures. Livewire friendships balance members’ need to ‘be a normal kid’ with their need to interact with other young people who can relate to their circumstances. The strength of Livewire friendships is evidenced by members’ continuation of their engagement with Livewire post-recovery.</td>
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<p>| Helping others enhances one’s sense of resilience. | Livewire members gain a sense of resilience through helping others in the Livewire space. |</p>
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<td>Cybersafety dominates discussions of young people’s online engagement. In these contexts ‘safety’ is defined in terms of protection from bullying and online ‘predators’.</td>
<td>Livewire members prioritise safety, but define safety as freedom from prejudice and marginalisation on the basis of their illness and/or disability. The issue of safety for Livewire members thus relates directly to issues of identity and embodiment. Understanding safety in the Livewire context requires broader notions of wellbeing and nuanced concepts of safety. Livewire provides an important function in the process of ‘transition’ for some members – the shift from identifying with chronic illness and disability to becoming young adults in the ‘real world’.</td>
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9. References


Levesque, J. (n.d.) *Starlight Children’s Foundation: Livewire Literature Review*. Children’s Hospital Foundation Research Institute, Westmead, NSW.


10. About the Authors

**Dr Amanda Third** is Senior Lecturer in the School of Media, Communication and Culture, and Director of the Centre for Everyday Life, a research institute dedicated to the study of cultural and communication practices. Dr Third has a research interest in the social and cultural dimensions of new media technologies such as mobile telephony. She is currently collaborating with Dr Ingrid Richardson on a Telstra Foundation funded project called ‘Moblogging and Belonging’ which investigates the potential for moblogging (blogging ‘on the run’ from a mobile phone) to enhance young people’s sense of social inclusion and connectedness. She has published on topics including: young people’s online and network engagements; the mobile phone as material cultural artefact; information and communication technology policy in the developing world; the media’s relationship to terrorism both historically and in relation to the current ‘War on Terror’; the politics of embodied identity; and the gendering of terrorism. Dr Third has participated in several university- and externally-funded collaborative research projects, and has a strong record in effectively communicating the results of her academic research via the mainstream media both nationally and internationally. Dr Third is a member of the Inspire Foundation’s Western Australian Advisory Board and the Technology and Wellbeing Roundtable coordinated by the Inspire Foundation and the Telstra Foundation. Dr Third is the current President of the Cultural Studies Association of Australasia, and is the recipient of the 2009 Murdoch University Medal for Early Career Research Achievement.

**Dr Ingrid Richardson** is Senior Lecturer in the School of Media, Communication and Culture at Murdoch University. Dr Richardson's field of expertise is socio-cultural and user interaction aspects of new and interactive media, with a particular focus on mobile and screen technologies. She has published on mobile and new media, including the iPhone, Web 2.0, location-based and mixed reality games, virtual environments, digital imaging, urban screens and sustainable technologies. She is working with Dr Amanda Third on the ‘Moblogging and Belonging’ project (funded by the Telstra Foundation), is currently project manager of an Australian Learning and Teaching Council (ALTC) project which focuses on user-generated web content, and a collaborating researcher on a serious games project funded by a Murdoch University Discoverers Grant. Dr Richardson is the recipient of the 2008 Murdoch University Medal for Early Career Research Achievement.

**Urszula Dawkins** is a freelance writer and editor who has worked for more than twenty years in a professional writing capacity with a range of arts industry, government, corporate and social welfare sector clients nationally. Since 1995, Ms Dawkins has also published a range of fiction writing and performed her work at festivals and events within Australia and overseas. In 2004, Ms Dawkins had a residency at the Iceland Writers’ Union’s Gunnarshúsin Writers’ Studio in Reykjavík, Iceland. In mid-2010, she will be the Marrickville Council Artist-in-Residence in Sydney. Ms Dawkins wrote the vignettes featuring Livewire members for this report.

**The Centre for Everyday Life (CEL)** at Murdoch University is a world class research centre dedicated to the study of technology and culture in everyday life, with an emphasis on young people’s day-to-day interactions with media and technology. Motivated by social justice values, the Centre undertakes cutting edge, qualitative research that focuses on technology’s role as an enabler.
Our researchers are at the forefront of new scholarship on the place of online and network communication technologies in the formation of identity and community. We have extensive experience collaborating with both commercial and not-for-profit organizations to achieve high quality research outcomes that can be applied to build capacity and improve service delivery, as well as contribute to the generation of rigorous research on the rapidly transforming contemporary media and technology environment.
11. Acknowledgements

The researchers sincerely thank Livewire members and their families for generously giving both their time and their opinions, and letting us into their lives for a brief moment to undertake this research. Their thoughtful responses to our questions have delivered insights that would not have been possible without their full cooperation.

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Thanks also go to Urszula Dawkins for compiling the vignettes featuring Livewire members for this report.

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