



## Performing health identities on social media: An online observation of Facebook profiles

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## **Performing health identities on social media: an online observation of Facebook profiles**

### **Introduction**

Characterised by interactivity, connectedness and multimodality, social networking sites (SNSs) such as Facebook and Twitter facilitate information sharing and the co-creation of new knowledge shaped by personal experience. Fox (2011) notes that over a third of US adults have accessed social media sites related to health while a survey by the US National Research Corporation found that the majority of people who use social media for health purposes indicated Facebook as their site of choice (NRC, 2011). Facebook, currently the social networking site with the largest membership base of over 1.3 billion users (Facebook, 2014) is a significant venue in which contemporary discourses around health and illness are produced, consumed and filtered (Hunt and Koteyko, 2015). In this context, clinical and policy literature have described SNSs as another source of 'patient empowerment' that fosters democratisation of healthcare (Koteyko et al, 2015). Critical voices, on the other hand, point out that this promissory view of an active 'e-patient', defined in terms of a neoliberal discourse of individual responsibility and risk management, serves to further extend the reach and power of medicine and marketisation of healthcare (Hunt et al, 2015; Powell & Boden, 2012).

In doing so, however, academic and policy communities have neglected to consider how individuals already employ social media to perform and negotiate health and illness identities. In contrast, in this study we approach SNSs as an important source of data on discursive practices and situated experience in relation to diabetes self-management. Diabetes mellitus is a metabolic disorder characterized by high blood sugar resulting from defects in the production of or response to insulin (Zimmet et al, 2001). People with diabetes often need to develop complex strategies for managing the condition on a daily basis that include glucose monitoring and insulin management, as well as access to education courses, psychotherapy and social support. They are therefore regarded as a group that may benefit substantially from the networking and information-exchanging functions of SNSs (Shaw and Johnson, 2011), and there is a growing number of webpages on Facebook and the web generally that are dedicated to providing support for people with diabetes (Greene et al., 2011). In this context, there is a timely opportunity to examine the role of social media in the lives of users with type 1 and type 2 diabetes and the online practices they employ in their ongoing representation of life with this long-term condition.

SNSs bring new material constraints and possibilities, new patterns of representation and a new social context within which health and illness identities are constructed (Koteyko et al, 2015). Platforms such as Facebook converge different means of interaction by allowing microblogging in status updates, the uploading and sharing of pictures, video clips and web links, and the use of chat windows and messaging options. As such, these sites are not only technologies of entextualisation (Bauman

and Briggs, 1990) but also technologies of *recontextualization* (Varis and Blommaert, 2014), in that they allow users to reuse and comment upon pre-existing content, tag various resources and through these actions make claims to identity. Indeed, previous research has revealed that Facebook users predominantly construct their identities implicitly through various activities on the site such as 'showing', rather than explicitly through language use (Locher and Bolander, 2014). In this study we therefore emphasise the need to attend to the presentational features through which illness experiences are reflected, and can be observed on social media sites, but which may not be coded linguistically. This is in line with the program of research advocated by Thurlow and Mroczek (2011) who call for the study of discourse, ideology and technology that incorporates the analysis of multimodality, as well as with the increasing recognition of the importance of gestures and images in the research on illness narratives (Riessman, 2008).

In examining how the issues of identity and chronic illness are presented and managed through actual interactions on the Facebook site we intend to contribute to the understanding of online diabetes-related representations and practices. In this context, our research questions are as follows: What are the linguistic and semiotic resources used by people with diabetes to manage and organise their identities on Facebook? How is their use of the site's architectural affordances involved in such identity construction? What can such identity performances tell us about the implications of SNS use for narrating illness experiences? We focus on how participants created content on their status updates and personal pages, how they engaged with content created by others, and for what social and rhetorical purposes.

### **Health identities in a mediatized society**

The constructivist position we adopt treats health and illness as 'political' categories (Fox 2002) that extend beyond physical characteristics of the body to include material and cultural possibilities and constraints. This position is shared by scholars studying illness narratives, who point out how everyday accounts of life affected by illness are inextricably linked to structures of power (Sarangi and Roberts, 1999).

As in today's society identities are also increasingly forged in the context of technologies ranging from digital media (Haraway, 1991), to cosmetic surgery and body modification through pharmaceuticals (Negrin, 2002; Potts, 2004) there is a recognized need to examine the place of social media in the everyday experiences of illness. However, although there is a growing body of research on online support for chronic diseases such as, for example, arthritis, fibromyalgia (van Uden-Kraan et al, 2008), irritable bowel syndrome (Coulson, 2005), different types of cancer (Blank et al, 2010) and diabetes (Green et al, 2010), these studies tend to focus on website-based patient support groups (rather than SNSs) and their instrumental uses. Furthermore, this body of research is dominated by psychological approaches which track difference at the level of psychological traits and therefore neglect race and gender inequalities together with the wider economic and social contexts (notable

exceptions research by Orgad, 2006 and Hunt & Harvey, 2015). For example, the act of sharing – of advice, information, or emotional support -- highlighted in this literature, is conceived in instrumental terms (as contributing or hindering the management of symptoms). From the perspective of self-presentation however, users of SNSs who choose to post about themselves or share condition-specific information are likely to be involved in much more than just ‘sharing’ -- they are negotiating specific social activities and, through this, they are performing specific identities in a situational as well as socio-political context (Mazanderani et al, 2013).

By contrast, linguistic research in computer-mediated environments is increasingly recognizing the importance of studying identity construction (Androutsopoulos, 2008; Herring, 2004, 2013; Hine 2000; 2008; Mondada and Locher, 2014). However, research on identity construction in SNSs, which constitute a ‘non-anonymous’ (nonymous) setting predicated on ‘anchored relationships’ (Zhao et al, 2008) is still relatively scant (Bolander and Locher, 2014). Such ‘nonymous’ environments, of which Facebook is one, limit the range of identity claims available and can hinder disclosure. In SNSs potentially distinct audiences such as acquaintances, friends, employers, as well as close family are collapsed into a single space which may lead to conflict between multiple presentations of self (Marwick & boyd, 2011). From the perspective of our data, for example, it is less likely that participants would claim fictional identities, engage in trolling, or perform acts of intimate self-disclosure facilitated by relatively high levels of anonymity (Suler, 2004).

Subscribing to the above-mentioned tenets, our approach aims to situate online contributions by people with diabetes in the relations of production, that is, in their institutional, political and interactional contexts. We intend to reveal how ‘being a person with diabetes’ is made observable and reportable via the affordances of social media, and how participants use, negotiate, or resist various cultural and technological resources available to them in this process. Although our analysis is informed by the medical sociology perspective, analytically we want to go beyond the mere identification of cultural and political resources to clarify *how* participant’s constructions are achieved discursively and multimodally – using the framework described below.

### **Conceptual framework**

In their review of methods for analyzing online data, Giles et al (2004) make a distinction between methods suitable for macroanalysis (such as social network analysis, text mining and ‘netnography’) and microanalysis performed through one of the linguistics-centred frameworks. While the authors present a convincing case for the development of digital conversation analysis, in this study we adopt the framework of discourse-oriented ethnography (Androutsopoulos, 2008) based around online participant observation as it allows a combination of the macro- and micro perspectives discussed above. In contrast to the study of log data extracted and detached from its social and cultural contexts, the framework allows to examine participants' situated use of social media and associated discourse practices and relate them to observable patterns of language use.

The aim of the ethnographic observation was to enter the participants' life-world as mediated through Facebook and to understand the roles it plays in relation to their diabetes and its management (Rampton et al, 2014). Hine (2008) discusses the value of active participation in the field as beneficial for providing first-hand experience of the communicative activities and practices in which the research participants are themselves involved. In our own case, active participation in diabetes-related networks on Facebook would be premised on having a diagnosis of type 1 or type 2 diabetes or caring for someone with the condition. As neither of the authors of this paper meet this criteria, we adopted a position of passive participation in diabetes-related Facebook groups and pages in which we read our participants' contributions but did not publish our own posts or comments<sup>1</sup>.

In focusing on the discourse of the participants, our observation was particularly concerned with the dynamics of participants' interactions, the activities performed on Facebook, and the semiotic (linguistic and visual) resources they used to achieve these (Androutsopoulos, 2008).

In line with the discursive psychology perspective, we view identity as 'negotiated performance' (Reynolds and Wetherell, 2003: 4), focusing on the way identity is socially produced, on-going, and managed at an everyday level (Billing, 1987). We were also interested in differences in the use of semiotic resources across the various communicative environments on Facebook and the different support functions they afforded the participants<sup>2</sup>.

## **Data and method**

Data was collated from a four-month ethnography that combined systematic observation of 20 participants' activities on Facebook with a direct follow up contact via in a semi-structured interview. Observation participants joined the study through a combination of recruitment by Diabetes UK and concurrent observational work

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<sup>1</sup> However, the process of subscribing to groups and pages also meant that their content was curated on the Newsfeed of the Facebook profile used in this study. Hence our own experience of logging into Facebook involved being confronted with posts published on diabetes groups and institutional pages in the same manner experienced by our participants.

<sup>2</sup> It is important to note however, that the type of language-focused ethnography is different from a long terms observation of a 'virtual community' as carried out by media and communication scholars, for example. Here we adopt elements of ethnographic method and follow Hine's suggestions that virtual ethnography remains necessarily partial and is an "adaptive ethnography which sets out to suit itself to the conditions in which it finds itself" (Hine, 2000: 65; Androutsopoulos, 2008).

examining the uses of peer-run diabetes groups on Facebook. Alongside previous work on organisational diabetes pages (Hunt and Koteyko, 2015), this concurrent work on groups also furthered our immersion into the network of diabetes-related peer support on Facebook, providing insight into some of possible uses of the site for publishing and sharing diabetes-related content.

The participants were between 21 and 65 years old, had communicated via Facebook in English for at least six months, and were purposively sampled to provide a balance across the categories of ethnicity and sex, and individuals with type 1 and type 2 diabetes (Table 1). Consented access to participants' contributions was provided via Friending a member of the research team, which made their personal profiles, Timelines and related activities available for observation<sup>3</sup>. Participants' profiles were visited every few days over the four month period to identify diabetes-related content which they had published. In addition, the researchers visited diabetes-related organisational pages to which participants had subscribed ('Liked') and the publically-accessible, diabetes-related Facebook groups which they had joined. Given the number of participants and the number of diabetes-related Facebook pages and groups to which they each belonged, this entailed extensive searching to identify participants' contributions across Facebook and the connections between their use of different Facebook groups and pages.

Observations were recorded through extensive field notes, screen shots of participants' posts and comments, and saving external webpages that the participants shared or linked to in their Facebook contributions. Contributions saved by screenshot were organised according to where on Facebook they were published (individual timeline, group, organisational page) as well as the type of activity they constituted (posting, commenting or 'liking') in order to build a picture of each participant's favoured Facebook environment and the sorts of activities they engaged in within them<sup>4</sup>. For this study we sampled mean contributions for each participant from each of the above-mentioned recorded categories: 9 diabetes-related posts on the participants' own timelines, such as status updates; 11 contributions to diabetes-related groups or pages; and 14 Likes of content on diabetes-related groups and pages.<sup>5</sup>

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<sup>3</sup> The University of Leicester Research Ethics Review board approved the project to which this paper contributes (Project Reference: nk158-f4cc9).

<sup>4</sup> The ethical and practical parameters of our study meant that several other Facebook environments were excluded from our field of observation, including individual messages, Facebook apps and closed groups to which we did not belong. However, these additional sites were discussed during semi-structured interviews with participants, alongside other SNSs and social media technologies that they used to mediate their diabetes management.

<sup>5</sup> It is important to note that the participants were not equally active in writing status updates or making contributions in groups and on pages, and that they also made non-diabetes-related contributions in different Facebook environments.

The challenges of coding multimodal data are well documented (Herring, 2013). In this study, the particular challenge was accounting for both the language use and the accompanied use of Facebook's features, such as sharing and 'liking' in the interpretation process. Here the solution was making 'action' the key point (Scollon, 2001) by focusing on what the participants were doing, and recording how this doing was performed, that is what modes were involved (and combined) in creation of particular meanings. From this perspective, a multimodal action of posting a status update about diabetes is comprised of the following: (1) linguistic elements related to self-presentation; (2) visual elements: the use of architectural features such as creating a profile, posting a status update, attaching pictures or video, tagging content or friends; (3) meanings: what to post, when, and for whom (imagined audience).

In terms of linguistic features we scrutinized each post in light of such concepts as stance-taking, including deictic referring (Hanks, 2005; Giaxoglou, 2015) and membership categorisation (Schiffrin, 1996; Reynolds and Wetherell, 2003). In recent research on social media these categories are merged under the term 'narrative stance-taking', which covers both the topic of the story and expectations about what stories to tell and circulate, and where; as well as who the teller is, and who is selected as audience (Georgakopoulou, 2013: 22).

The resulting procedure is documenting both 'linguistic' and 'visual' information about particular actions (Bollander and Locher, 2014: 19). This information was discussed together and used at the same level of coding – for example, the linguistic construction of expertise through the use of medical terminology in a group discussion comment was seen as inseparable from the act of posting (using the Facebook's comment feature in specific groups) and the use of hyperlinks to share relevant information. In this way, as van Leewen (2008: 8) points out, the study of multimodality pushes the linguist to view speech acts as multimodal microevents in which 'all the signs present combine to determine its communicative intent'. Furthermore, meaning does not arise only from the interaction in the moment but also resides in 'information, resources, expectations and experiences that originate in, circulate through and are destined for networks and processes that can be very different in their reach and duration' (Rampton, 2014: 2, citing Bauman & Briggs 1990).

## **Analysis**

The analysis resulted in different communicative actions and focused on how and for what purpose such acts were performed in this particular online environment. Following the above protocol for coding multimodal data, we identified four intersecting actions carried out by participants in their use of Facebook in relation to diabetes: 1) constructing personal expertise in relation to diabetes management; 2)

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displaying the individuals' integration into wider diabetes-related networks, 3) reporting on mundane aspects of self-management, and 4) using play to negotiate professional and cultural expectations of diabetes self-management. All of these actions illuminate how our participants recruited the different modes of performance and self-presentation enabled by SNSs, or indeed 'social awareness platforms' (Papacharissi, 2012), in communication about their chronic condition.

#### *Constructing personal expertise in relation to diabetes management*

Performance of this multimodal action draws attention to the ways in which participants assumed the role of a lay expert (Armstrong et al, 2011) through sharing and discussing diabetes-relating information on their personal profiles, Facebook pages and groups and the use of first person deixis. As noted in other online health communication contexts (Morrow, 2006), during discussions and advice-giving contributions, Facebook users typically include references to their own diabetic status and their experiences with the condition as a means to signal their competence as an advice-giver. Membership categorization devices used by the participants to refer to themselves and their audience include *diabetic, a person with diabetes, Type 1, T1, or Type 2*. For example, one participant responded to a question posed by a parent of a teenager with type 1 diabetes regarding the use of an insulin pump, simultaneously suggesting a course of action, evaluating this proposal and supporting her suggestion through a final claim of extensive experiential knowledge of type 1 diabetes:

Why not get him to call his nurse or pump trainer then discuss the advice and decide together what's best? Partnership is best - give him support in making decisions and let his 'empowerment' over his pump management grow. (I've had T1 for 49 yrs and never had any support as a teen!)

Participant 1, type 1 diabetes, 19-08-2014

Some participants positioned themselves as translators of recent developments in the medical field and used the content-building and sharing tools of Facebook to provide on-going updates and comments. By using Facebook's 'Like' feature, participants frequently affiliated with and informational posts published on the pages of diabetes organisations, providing a visible acknowledgement that they had consumed that content.

Occasionally, such content was then shared by the recipient among his/her network and accompanied by evaluative commentary. One participant shared a link to an online article about a new glucose monitor system which relies on the sensor attached to the arm eliminating the need for finger pricking, endorsing it through his positive evaluation:

The way forward for blood testing.

Participant 2, type 1 diabetes, 08-11-2014



Lay expertise assumed in such posts complemented rather than contradicted existing medical guidelines. For example, recommendations for lifestyle choices (exercising or taking vitamins) were legitimised both through reference to medical advice as well as personal or social experience:

I take vitamin B complex it is recommended by the medical profession for T2s  
Participant 18, type 2 diabetes, 03-03-2015

The same participant also announced his creation of a new page for 'Type 2 Diabetics not on insulin medication' through a status update. In describing the aims of this virtual 'bootcamp' for those who are 'really serious about effectively managing their T2 Diabetes', the participant stressed the importance of diet and exercise, backing this by reference to his own experience: 'I have found that you need both diet and exercise BS down to below 6.5 (117)' (02-01-2015).

### *Building and maintaining diabetes-related networks*

Whereas construction of personal expertise was evident through the use of first person pronouns, references to medical terminology, and information or fact-oriented content, performance of this action was characterized by expressions of solidarity, the use of affective language, and explicit selection of diabetes-related audience both in status updates and contributions to groups. This involved sharing and 'liking' humorous and motivational content related to diabetes, posting about online and offline events, and addressing the audience using inclusive personal pronouns and membership categorization devices signaling group allegiance (for example, 'people with diabetes', 'For all my UK Diabetes friends', 'any of you guys').

In the following example, a participant negotiates her position among the members of the diabetes-related group through the shift from first person singular pronoun to first person plural, after selecting 'UK Dexcom CGM users' as the direct addressees of the post:

Info for **any UK Dexcom CGM users**: I've often wondered whether my BG control actually affects the longevity of the Dex sensors (can't ask Dexcom as they only approve them for 7 days, but we all know they last far longer).[...]

Participant 1, type 1 diabetes, 05-09-2014

Activities involved the use of 'likes' to display association with motivational rather than factual content shared on pages created by organisations and groups. As Page (2012) points out, the use of comments and 'likes' in social media allows users display their engagement with others and their position within a social group. Some group posts used collective references ('people with diabetes') to challenge aspects of local (NHS) provision, or sought to elicit other group members' views on unsuccessful consultations with GPs. Furthermore, when sharing visual content participants used captions or comments that signalled a sense of belonging to a network (see Figure 1 below), such as 'things only a person with diabetes would



Figure 1 – Post 'liked' by participant 2, type 1 diabetes, 19-11-2014.

understand', 'Hard to explain to someone who has no clue' or 'Share if you know someone with Diabetes' .

Just as in face-to-face communication, the choice of inclusive lexis in status updates implies a specific audience, and can make some audience responses more relevant than the others. Whereas the membership categorization device 'UK diabetes friends' is explicit and specific, the evaluative lexis, interrogatives and exclamation marks (as in the above post in Figure 1), and the non-linguistic content (e.g. humorous images about diabetes) are more subtle strategies of selecting an audience and the type of a response sought. It is in this way that stance taking in social media 'indexes affiliation with certain readers more than others; it address some readers more than others' (in this case others who take a similarly wry attitude

towards their diabetes) which can be seen as a strategy to counteract context collapse in SNSs environments (Georgakopoulou, 2013: 27).

Although we observed a variety of themes in images and language used and shared by participants as part of such online social exchanges, the emphasis was on sharing good-natured and humorous posts and providing expressions of positive reinforcement. In seeking and selecting other people with diabetes as co-tellers of their optimistic posts (both implicitly through person deixis and membership categorisation and more explicitly through name tagging), the participants were co-creating unspoken norms around the content and style of diabetes-related posts. For example, one participant shared news about an online training course 'MySugr Academy – Tame Your Diabetes Monster' using name tagging to select members of the audience 'Very exciting times at MySugr headquarters. [...] Congratulations FXXX and MXXX!, as well as provided a wry commentary on the '50 Shades of Diabetes' video he shared (Figure 2):



Figure 2. Post shared by Participant 9, type 1 diabetes, 11-11-2014

In one instance, such norms were partially spelled out when the participant (mentioned in the above sub-section) created a page for help with managing T2 diabetes and described its aims as follows:

This is not a place for those that want to make excuses that they 'can't live without sugar in their tea or not eat bread' or whatever. [...] As it is a bootcamp that means there's no room for whinging or complaining about our condition (there's plenty of groups that cater for that). This means that we take responsibility for the management of our condition and no amount of blaming others or circumstances is going to change that.

Participant 18, type 2 diabetes, 02-01-2015

The activities we observed in this category demonstrate that Facebook users with diabetes talk, provide support, and help each other online and, as indicated in their responses to Events posted within diabetes-related groups, that they may also meet offline. The language of status updates suggests that they display a sense of belonging to the network or, in Anderson's terms (1983), to an "imagined community" that is oriented to verbally and multimodally using images and the user tagging function provided by Facebook. This is the sense of connection, often attributed to users of online support websites as well as SNSs, that participants feel through a community affiliation even though they may have never met.

The multimodal actions we have described so far indicate that participants use diabetes-related groups and pages as separate spaces within Facebook as they are set apart from their own personal profiles, in this way addressing potential tension between their everyday performance of selves in status updates and their projection of their identity as a person with diabetes. In what follows we turn to multimodal actions performed mostly through the use of status updates, which provide instances of the strategies adopted by the participants to address the 'context collapse'.

#### *Reporting on mundane aspects of self-management*

In addition to research-based information and discussions of medical guidelines, participants used first person deixis to post about their daily experiences including descriptions of symptoms, daily routines, incidents of pushing oneself too hard, records of stress levels, and blood sugar levels. When posted in the form of status updates, online contributions orient to Facebook's emphasis on recency through the use of temporal deixis (Page, 2012). In the following examples, a participant uses 'this morning' and 'today' to anchor events in time and render them reportable to an audience. She also draws heavily on evaluative lexis to encode a negative stance and elicit support:

2 hypos already this morning...today does not look good. Stupid insulin. Grrrr.  
Damn it! Forgot to change my cannula again!

Participant 3, type 1 diabetes (11-09 and 10-11-2014)

The encoding of emergency through temporal deixis in combination with the projection of negative stance constructs the post as a 'demand' post that calls for support and compassion from the audience (Giaxoglou, 2015). In the above instances, such strategy is successful in that the participant receives follow up comments expressing sympathy and support from members of her own network.

In addition to posting status updates to chronicle day-to-day (or hour-to-hour) changes in one's condition, the use of status updates enables users to inform their friends of their location. This is realised either through direct references to places ('Waiting for my annual eye check at a clinic in Wood Green' participant 4, diabetes, 03-09-2014) or through location tags and Facebook-integrated apps to visually display the users' movements. In the case of Figure 3, below, participant uploads the

results of a walk along with distance, time, speed and calorie figures to illustrate the exercise she has taken that day, thus entextualising this activity in a context in which it can be commented on by herself and members of her online network.

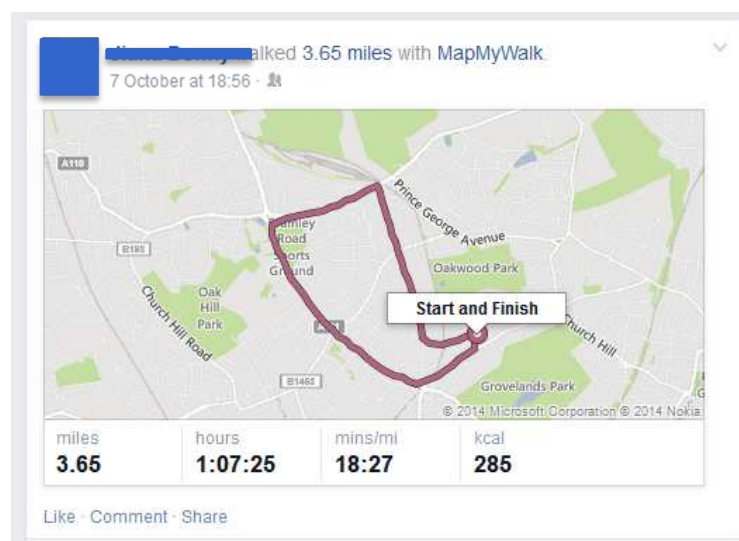


Figure 3 - Posting results using MapMyWalk app that provides a map of the area walked. Participant 4, type 2 diabetes, 07-10-2014

The use of status updates allowed our participants to centre on their experiences in the here-and-now and receive support from diverse groups in their own network (rather than only online peers with diabetes). In other instances, however, users' reports of their daily management were also provided in their interactions with diabetes organisations who operate on Facebook. For example, participants added responses to questions such as 'Have you had your flu jab?' posted on a page run by a diabetes charity and 'What have you had for breakfast this morning? 😊', posted on a popular commercial organisation's Facebook page (Hunt and Koteyko, 2015 provide a detailed analysis of such posts). These comments both allow the users to entextualise their routine management practices and potentially seek additional responses from the wider network of individuals who comment on these posts.

#### *Using play to negotiate social and professional expectations of diabetes self-management*

Status updates and comments coded in this category recruited humour and/or irony as a key strategy of self-presentation. Performances in SNSs often recruit linguistic play and reversal of norms to bring 'affective processes which infuse new meaning into the texture of a performance' (Papacharissi, 2012: 1993; Sedgwick 2003). This process is further supported in SNSs through the availability of different architectural 'props' (videos, pictures) that offer a heightened potential for theatricality and drama (Parks, 2010). Papacharissi (2011), for example, posits that play allows individuals to 'mix public and private to deconstruct, and transform performances in

search of an authentic sense of self'. In this way, performance becomes disclosure, or "a public way to show private stuff" (Schechner, 2003: 265).

For example, in our sample, participants used the unique features of the SNSs sites as well as linguistic strategies of play in order to highlight pleasurable and 'normal' aspects of everyday life where diabetes was presented as only a small part. One participant took part in the Facebook 'challenge' where friends nominate each other to do a chosen set of activities (announced through status updates). This challenge involved sharing 'things you may not know about me' and is one of many strategies facilitating disclosure and sense of connection in online social networks. The participant took up the challenge by providing a long list of recreational and spiritual activities (singing and tap dancing, performing in West End, believing in God) and 'too many hobbies' (wood turning, scroll sawing, fishing, gardening, golf, and music), and only briefly referred to diabetes among other biographical facts (participant 19, type 2 diabetes, 01-02-2015)

Posts in this category did not always limit the audience to members of diabetes community. This is evident through the absence of specific terms of address, as well as through responses in comments (e.g. commenters disclosing in some way that they do not have diabetes). In contrast to the above mentioned status update where a participant provides his expert evaluation of a diabetes technology ('The way forward for blood testing'), status updates in this category recruited irony and/or membership categories from pop culture to construct a playful, non-serious stance in relation to their condition<sup>6</sup>:

Pray that The Precious get delivered tomorrow. I need my Dexcom sensors.  
I'm a cyborg.

Participant 7, type 1 diabetes, 16-09-2014

Such uses were supported via the multimodal affordances of the platform. In Figure 3, for example, a recently diagnosed participant uploaded a picture of his arm with a state of the art glucose monitoring system attached, accompanied by a similar reference to a man-machine system popularised in science fiction literature and movies.

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<sup>6</sup> We treated instances of humour as part of this category. However, the same instances of humour can also be subsumed in the actions described above, since displaying a sense of humor contributes to the construction of solidarity and can be used to signal group allegiance (Varis and Blommaert, 2014).



Figure 3: Example of a playful identity construction (Participant 20, type 1 diabetes, 02-04-2015)

The participant uses the photo to imbed the event in 'offline' experience and render it 'authentic' (Tagg, 2013) while also projecting a playful stance and an optimistic narrative of technologically-assisted ideal glucose scores. As scholars of disability studies (Reeve, 2012) point out, here the cyborg metaphor is used with celebratory undertones since a body that results from the technological intervention is deemed to be a success (the post anticipates the author's 'target glucose' in the future).

The resulting success story resembles narratives of conquering illness (Frank, 1995) and is further encoded through 'liking' and sharing the humorous content. In contrast to posting memes to diabetes-related groups or addressing peers with diabetes (as is done in Figure 2 above), participants sometimes shared memes on their walls without pre-selecting users who have diabetes (Figure 4 below).



Figure 4: Participant 8, type 2 diabetes, 14-01-2015

In such instances, the sharing of humorous content directly with members of one's own network can be used to draw attention to the difficulties of living with diabetes and constant self-management, while also signaling both a (relatively) light-hearted approach to the condition and its seriousness.

Overall, the use of linguistic resources of humour and irony together with Facebook's affordances allowed our participants to present multiple and mutable aspects of their identities while keeping a unitary profile, and enabling performances of authenticity not only as entitled members of diabetes-related groups and expert diabetics but also as friends and relatives living with a chronic illness.

### **Discussion**

In setting out to examine identity construction by people with diabetes on Facebook, this paper relied on the premise that the actions people with diabetes were involved in as part of (or against) collectivities to which they consider they belong, can be revealing of how they view themselves and others. This in turn provides understanding of how our participants want to manage their chronic condition in the everyday and what social, political, and cultural resources they have to mobilize to support them in these endeavours.

The different actions performed by the participants on Facebook demonstrate that online social networking is a locus of different concurrent practices: not only empowering, but also both resistant and compliant. First of all, the participants sought and provided mutual support through building or maintaining social



networks, which points towards empowering practices in these online spaces. Ziebland and Wyke (2012) identified connecting to others and narrating experience as one of the key domains through which online activity can affect health. Our analysis of activities on Facebook support this thesis as the observed practices of producing experiential knowledge, reporting everyday stories of success and failure to manage blood sugar levels, and disseminating information can be used by the participants to improve management of diabetes and may give them a sense of greater agency.

The practices of reporting on mundane experience and maintaining social connections, in particular, are inextricably linked to the architecture of the social networking platform and have been described as 'participatory surveillance' by Albrechtslund (2008) in contrast to more top-down, hierarchical views of surveillance:

Online social networking can also be empowering for the user, as the monitoring and registration facilitates new ways of constructing identity, meeting friends and colleagues as well as socializing with strangers. This changes the role of the user from passive to active, since surveillance in this context offers opportunities to take action, seek information and communicate.

(Albrechtslund, 2008, no page)

As evidenced by their use of the multimodal affordances of Facebook these new ways of constructing identity have been embraced by the participants in our study. As carriers of socially shared meanings, status updates helped our participants convey and enact stories and relationships. Drawing on linguistic play and cultural references in their public disclosure of information about the condition, the participants also harnessed the Facebook's potential for 'deliberate improvisation':

..the *as if* aspect of play supports a premise for the convergence of private fantasy and public disclosure that may make individuals more comfortable expressing thoughts they would otherwise withhold.

(Papacharissi, 2012: 1998).

In the case of chronic illness, such mode of expression can be used to negotiate expectations of strict compliance with medical guidelines and redefine the social meanings of physical and mental changes associated with diabetes.

At the same time, however, the range of voices and emotions we have observed in this study is rather limited. Clinical literature about the potential of the SNSs in healthcare typically asserts that the use of the new interactional tools can encourage patients to voice a range of concerns and potentially challenge medical expertise (Koteyko et al, 2015). Although we observed instances where participants discussed and challenged medical expertise and expressed negative emotions, such topics were not frequent or popular in our sample. Instead, by articulating and performing the optimistic narratives of lay expertise, Facebook users with diabetes reproduce a

neoliberal narrative premised on individual responsibility for illness and its management. This tendency was further underlined by activities performed as part of the 'building and maintaining networks' category where sharing and liking motivational and cheerful memes was predominant.

Similarly, in contrast to studies that highlight the importance of playful identities in promoting activism and social movements, the activities we observed were seldom recruited to foster political discussions around access to healthcare provision or social causes of diabetes. Rather, they were used to present a story of coping with disruption, and asserted the individual's resolve to maintain a 'normal' life and not being 'defined' by the condition.

Stommel and Koole (2010) offer an insightful analysis on the role of the power of the peer to define and ascribe illness status in a website-based online community. While participation in SNSs is characterized by 'context collapse', our participants did nevertheless take care to articulate and display their relationship to a wider community of people with a similar condition. This was most evident through the use of narrative stance taking in status updates (notably, choice of member categories and terms of address), as well as through the content of online 'memes' they chose to share. In selecting, circulating, and commenting on motivational and humorous posts, the participants invited further contributions of this kind, promoting the cultural imperative to stay resilient and hopeful. Such emphasis on optimistic content is also a response to the tension arising from collapsed contexts, as participants were adopting the lowest common denominator strategy: as there are diverse audiences for whom a message may not be intended but who would receive it nonetheless, only 'unproblematic' content can be posted (Hogan, 2010; Sandaunet, 2008). While this positive outlook may be instrumental in helping some participants cope, for those who want to convey other emotions or engage in critical discussion, such a stance functions as an exclusionary mechanism.

## **Conclusions**

The analysis offers an interpretation of the way in which user contributions on Facebook become mechanisms where diabetes self-management is negotiated and defined as part of a social network, and away from the medical model and professional guidelines.

The site's architectural affordances provide a unique forum for the negotiation of identity, yet this is not space void of social and cultural expectations. Even as relatively "new" communication technologies, SNSs are not as revolutionary as their advocates would have us believe (Thurlow, 2013) and are embedded in the practices of everyday life as well as in pre-existing social, economic and political structures (Herring, 2004; Koteyko et al, 2015). Although the participants shared important information and provided social support, the communicative actions they performed via SNSs play into neoliberal ideologies that maintain that the individual is primarily responsible for their wellbeing. Whether constructing their own expertise in the

management of the condition, reporting on the everyday aspects of its management or experimenting with different ways of self-presentation, participants oriented themselves to the cultural imperative of creating and sharing narratives of optimism and resilience, looking 'on the bright side of things' (Lorde, 1980: 74).

The convention to post mostly about optimistic scenarios and emphasis on cheerful stories is well documented in research on online support groups. Whereas scholars such as Orgad (2006) and Bock (2013) have pointed out that users of support fora face pressure to produce a success story of how they cope with their illness, for SNSs users the situation may be exacerbated by the (sometimes) unspoken norms and affordances of the sites. Although the rhetoric and politics of 'happiness' and its institutionalization predates the use of SNSs, social media have played an important role in the reception and dissemination of claims about life as one would want to live it. Fostering social connections through performances of authenticity and the use of 'affective talk' (Page, 2012) to express personability, solidarity and emotional closeness plays into the commercially-driven imperative of the online networking platforms that harvest data from targeted user bases. We hope to have shown that this has important implications for the analyses of illness identities in non-anonymous environments, as the corporate ownership of such platforms and wider neoliberal politics of health present significant constraints to achieving the ideal of 'patient empowerment' in online spaces.

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## Appendix

Table 1. Observation participant information

| Participant number | Age | Sex    | Diabetes type | Reported ethnicity |
|--------------------|-----|--------|---------------|--------------------|
| Participant 1      | 62  | Female | Type 1        | White British      |

|                |    |        |        |                       |
|----------------|----|--------|--------|-----------------------|
| Participant 2  | 63 | Male   | Type 1 | White British         |
| Participant 3  | 26 | Female | Type 1 | White British         |
| Participant 4  | 43 | Female | Type 2 | Middle East & British |
| Participant 5  | 44 | Female | Type 2 | East African          |
| Participant 6  | 53 | Female | Type 2 | White                 |
| Participant 7  | 32 | Female | Type 1 | Caribbean             |
| Participant 8  | 55 | Female | Type 2 | White British         |
| Participant 9  | 26 | Male   | Type 1 | White British         |
| Participant 10 | 28 | Female | Type 1 | White British         |
| Participant 11 | 26 | Male   | Type 1 | White British         |
| Participant 12 | 44 | Female | Type 2 | White                 |
| Participant 13 | 31 | Female | Type 1 | White British         |
| Participant 14 | 61 | Male   | Type 2 | White British         |
| Participant 15 | 56 | Male   | Type 2 | White British         |
| Participant 16 | 22 | Male   | Type 1 | British Asian         |
| Participant 17 | 48 | Female | Type 1 | African-Caribbean     |
| Participant 18 | 63 | Male   | Type 2 | Irish                 |
| Participant 19 | 49 | Male   | Type 2 | Sri Lankan            |
| Participant 20 | 27 | Male   | Type 1 | White British         |

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