



A Day in the Life

What happens when you ask people who live with mental health difficulties to write about their everyday life?

1. Introduction

A Day in the Life was a one-year crowdsourcing project conceived and carried out by Social Spider CIC that asked people living with mental health difficulties one very simple question: What was your day like? What made your mental health better and what made it worse?

On four calendar days between November 2014 and August 2015 via an open appeal, the project asked people who identified themselves as living with a mental health difficulty to write up to 700 words about what their day was like.

These accounts of ordinary days lived with mental health difficulties were then published on the internet, unedited at www.dayinthelifemh.org.uk for anyone to read. They represent the largest single collection of accounts of the everyday lives of people with mental health difficulties.

Over the year, 893 different days were written by participants, or nearly half a million words, giving a window into the everyday lives of people with mental health difficulties.

When people signed up to the project they were told:

“We’ll categorise your day based on what things you mention in your account. We are categorising entries

for two reasons. Firstly: so that once uploaded it is easy for people reading to find days that feature experiences they are interested in; and secondly so that we will be able to put together simple reports talking about broad trends for interested readers based on all of the uploaded stories.”

People taking part were encouraged to remain anonymous and not to give details that would make their account identifiable. They were also encouraged not to compromise the privacy of others and not to write about institutions or services by name. Participants were asked to submit broad demographic details with each post such as age, gender, type of place they lived, whether they had any other long term health difficulties and what they felt their primary mental health difficulty to be. This demographic information was optional. People may at any point withdraw their submitted work from the online archive at www.dayinthelifemh.org.uk.

With funding from Public Health England, Centre for Mental Health and Social Spider CIC carried out a limited content analysis of 782 of the uploaded days seeing what, if anything, all of these days told us overall about what affects the day-to-day wellbeing of people living with mental health difficulties.

2. What did people write about most?



Figure 1: Topics most mentioned which had a positive or negative effect on the wellbeing of the writer

Figure 1 shows at a glance which topics were most mentioned having either a positive or negative effect on the wellbeing of the writer in the 782 days that were analysed.

The theme recognised in the greatest number of analysed days was experience of mental health services, whether this was positive or negative.

This suggests that mental health services have a centrality in many people’s experience of life with a mental health difficulty and contribute both negatively and positively to how they feel about their overall wellbeing.

The second most frequently mentioned area was work contribution, covering the feeling that work had contributed either negatively or positively to the sense of wellbeing of the person living with mental health difficulty on the day in question.

The third most mentioned area was home life - stability, security, routine - the sense of home as a safe environment in which to live. The fourth was friend support, the ability and opportunity to talk to and gain support from friends. Fifth was sense of purpose in life as a

positive contributing factor to wellbeing or its absence contributing to a lack of wellbeing.

Together, work, home life, friend support, partner support and a sense of purpose map well onto the conception of an individual sense of wellbeing being related to having something to do, somewhere to live, some people to love and something to be.

The sixth most mentioned theme was sleep; the sense that poor sleep and good sleep contributed to how the person writing felt. It is interesting to note that sleep is rarely discussed in terms of the wellbeing of people with mental health difficulties; disruptive sleep being seen often as a symptom of mental health conditions rather than as an experience in its own right.

Hobbies were the seventh most recognised theme; whether carried out for fun or as a distraction from more negative concerns. This included both the positive pleasure, enjoyment, relief or distraction that hobbies bring and also the frustration, sadness, or sense of loss that their absence, or the inability to either carry them out or derive satisfaction from them, can

bring. Things to do for personal enjoyment or enrichment are an obvious area for wellbeing.

The eighth most mentioned theme overall was medication, covering the effects of medication and the feelings of the individual about them. Medication was mentioned less than the experience of mental health services and was recognised more often in the analysis as being written about positively, rather than negatively.

The ninth and tenth most mentioned themes overall were partner support - whether the romantic partner of the individual writing understood and supported them or not - and self-stigma - the extent to which people regarded themselves negatively or positively in relation to their mental health difficulty and how that affected their wellbeing on the day in question. We could see these as indicating that how we see ourselves and how the people closest to us see us is an important element of wellbeing.

The eleventh most recognised area was the physical health of the individual. The twelfth was whether the individual felt that their day was made better by the support of their family. The thirteenth most mentioned area was the absence or presence of workplace understanding of their needs. The fourteenth most recognised area was whether the individual on that day had used a self-therapy technique which had contributed positively or negatively to how they felt. The fifteenth was whether the individual regarded exercise as having a positive or negative impact on their wellbeing during the day about which they were writing.

Positive effects on wellbeing

Figure 2 shows at a glance which topics were most recognised as having a positive effect on the wellbeing of the writer in the 782 days that were analysed.

Looking at the most commonly mentioned positive wellbeing indicators we see that the top three are friend support, home life, and sense of purpose. These are closely followed by positive experiences of mental health services, positive experiences at work and hobbies.

This indicates that having friends who understand your mental health difficulty is important; that feeling safe and secure at home is a vital contributing factor for wellbeing; and that having a purpose in the wider world is a vital component in a sense of whether 'today was a good day'.

Having a positive experience of mental health services seems to be important, as does an experience of working life that leaves you feeling as if something has been achieved or that the demands of the work did not overwhelm or reduce your subjective wellbeing.

The next three most mentioned positive themes were partner support, medication and physical health. The support and understanding of those closest to you and romantic and emotional partnership reinforce the importance of relationships to our wellbeing. Other positive factors focused on the importance of being around people, whether at work, through social life or by using social media: indicative perhaps of the importance of loneliness and isolation.

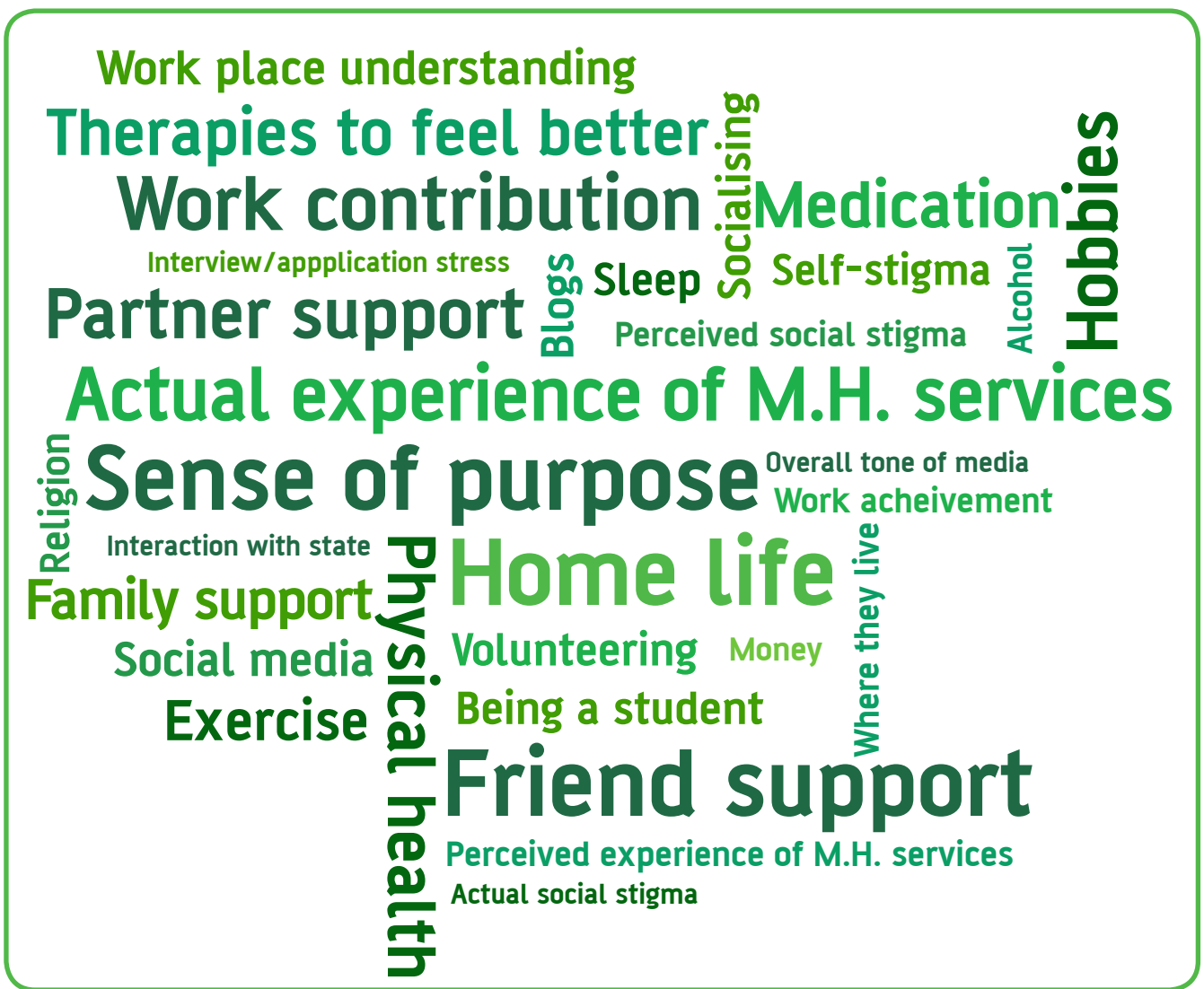


Figure 2: Topics recognised as having a positive effect on the wellbeing of the writer

Negative effects on wellbeing

Figure 3 shows at a glance which topics were most mentioned as having a negative effect on the wellbeing of the writer in the 782 days that were analysed.

The three most common themes recognised by our analysis process as representing negative wellbeing impacts were experiences of mental health services; poor or unsatisfying sleep and the physical health of the individual writing.

While it is not possible to break down the exact nature of the negative experiences of mental health services, it is possible this covers a wide range of concerns and issues. Some of the negative experiences of mental health services could be related to the quality of support they

were receiving, while others may be due to an absence of support or being made to wait for it.

The frequency with which poor sleep and physical health were discussed indicates the importance of the interaction between physical and mental health in the life of the individual.

The fourth most recognised negative theme was work, underlining the dual capacity of work both to create positive wellbeing and to undermine it. The exploration of the experience of work from the perspective of those experiencing ongoing mental health difficulties may provide some interesting insight into its impact on wellbeing.

The fifth most recognised negative theme was self-stigma; our internal self-judgement of our own worth and how much we do or do not accept our mental health condition. The negative experience of self-stigma may involve self reproach for perceived faults attributable to our mental health conditions. It could also be seen as how bad we feel about feeling bad;

something where we draw our cues from the social attitudes of those around us.

The sixth most recognised negative theme was an experience of home life that was not nurturing, sheltering or conducive to feeling like life was good. This could cover everything that happens within the four walls of a home.

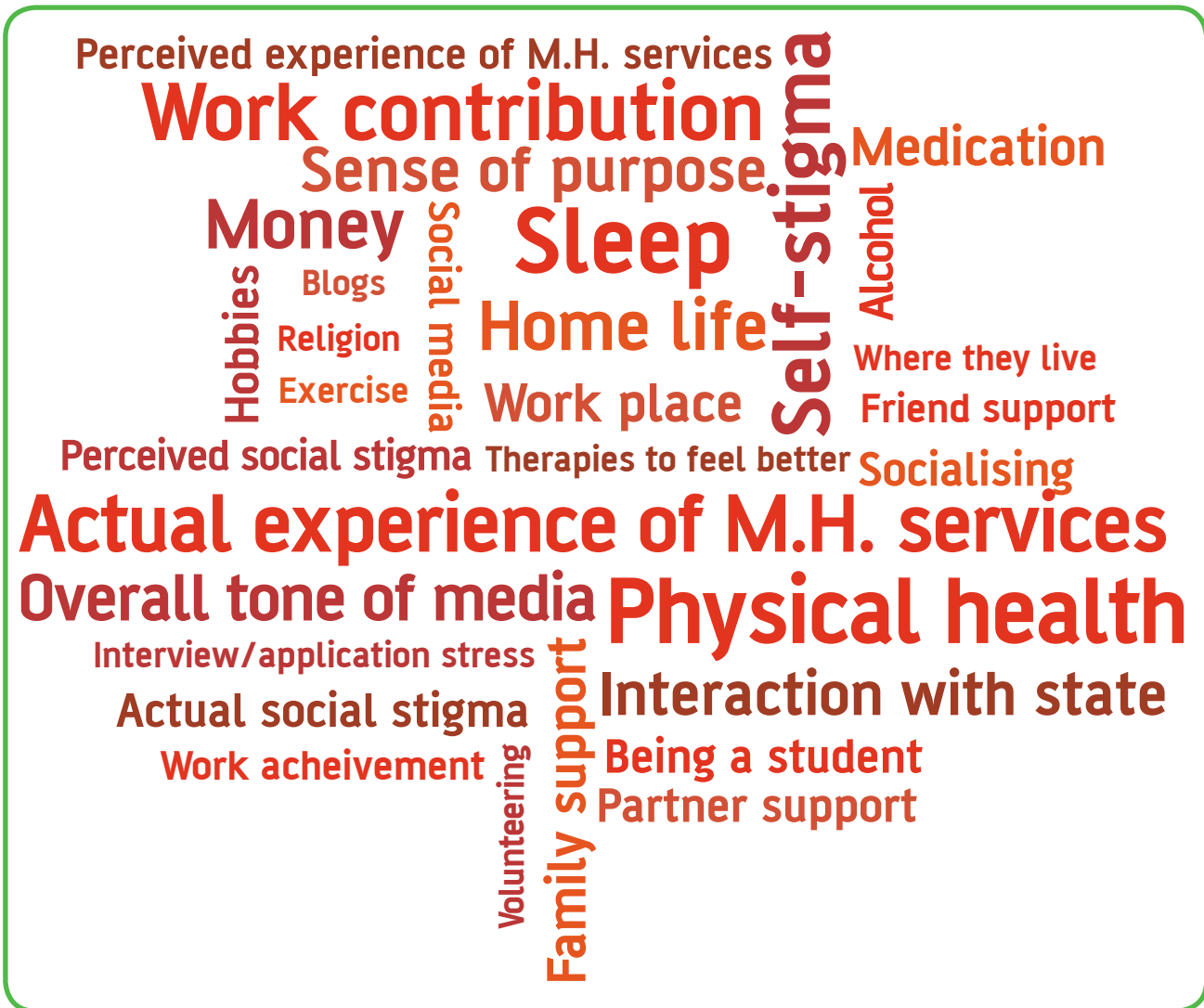


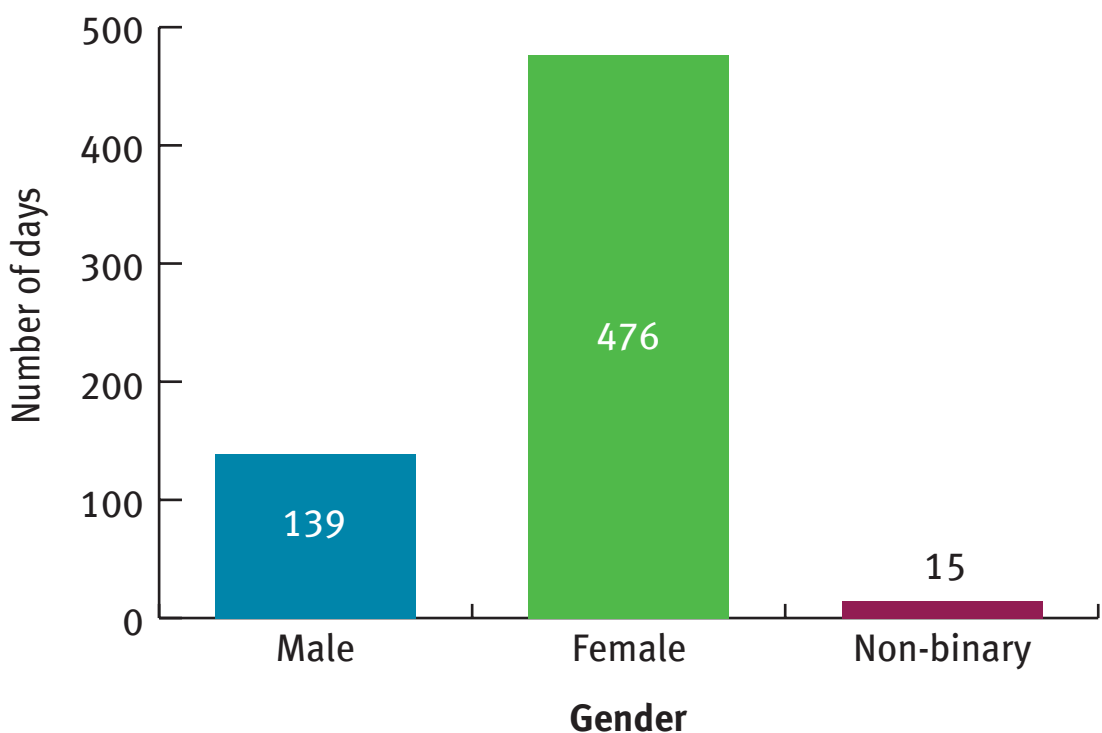
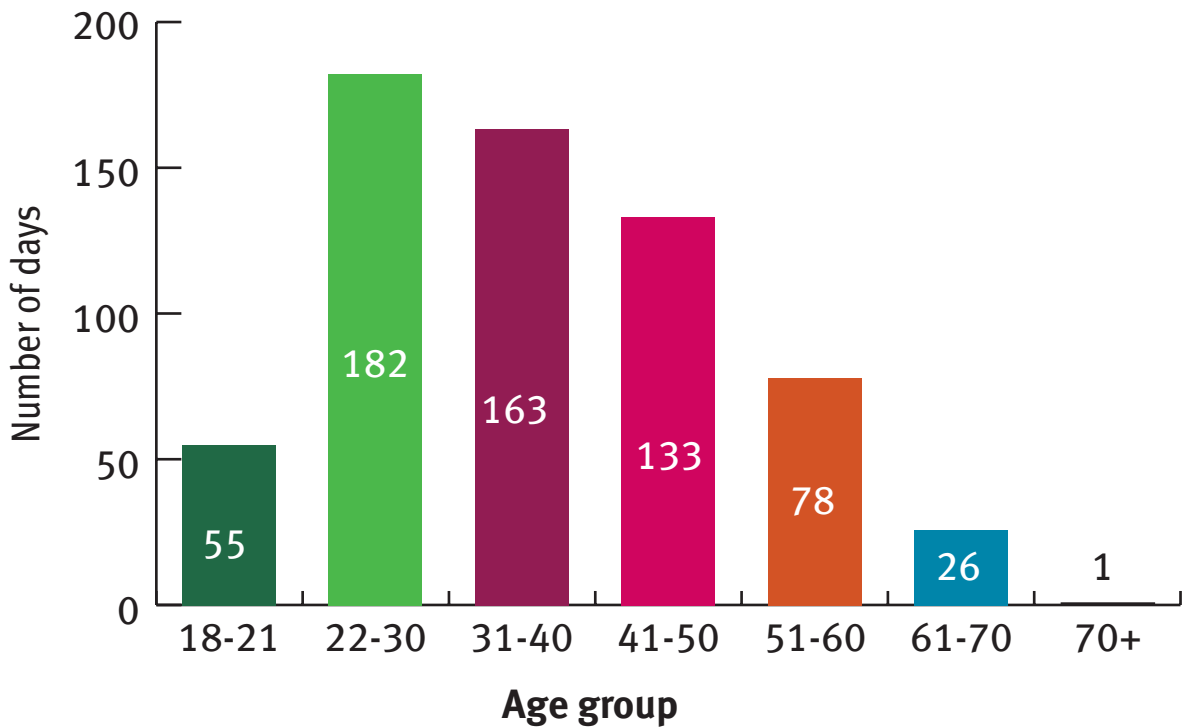
Figure 3: Topics recognised as having a negative effect on the wellbeing of the writer

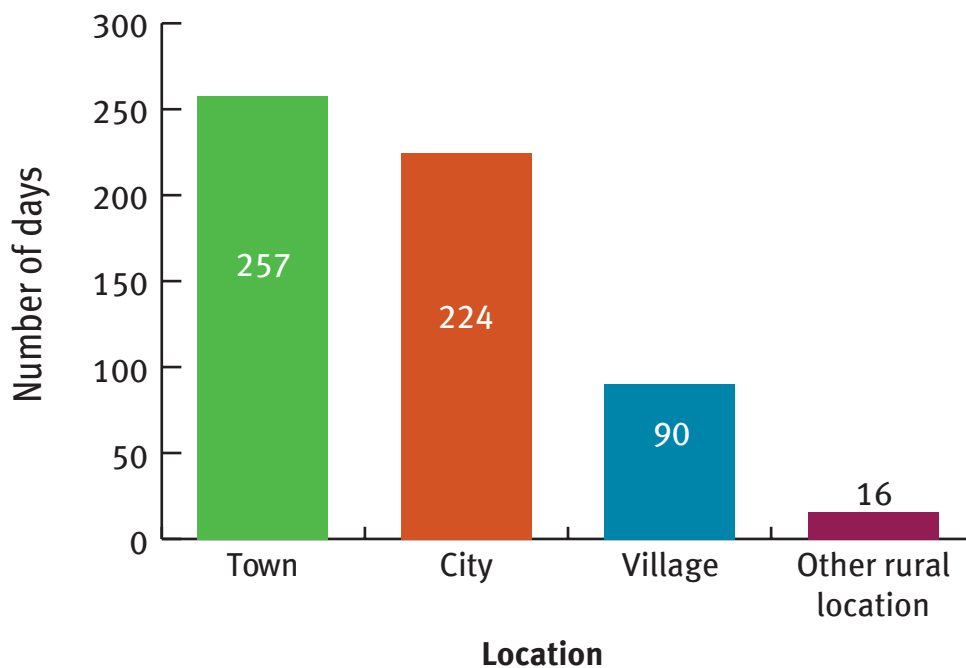
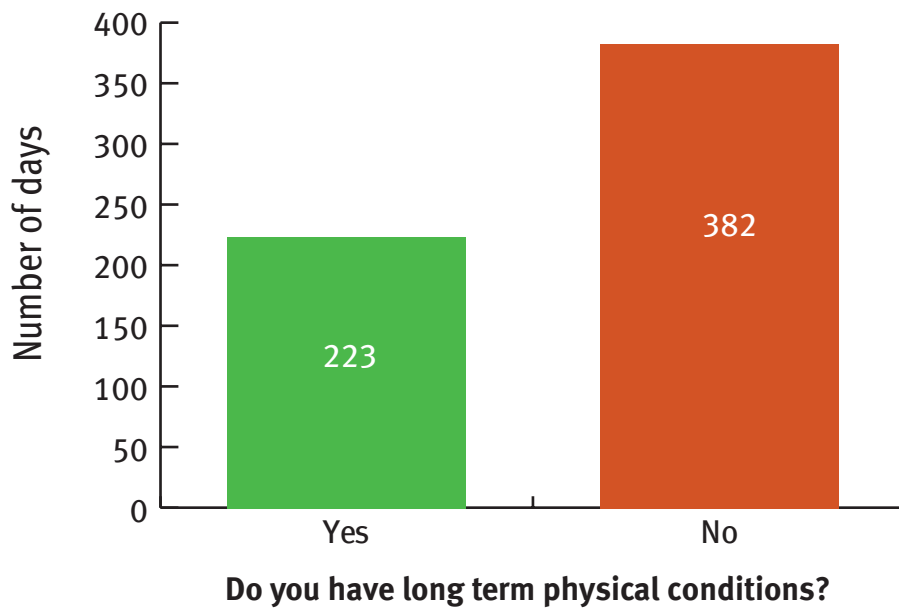
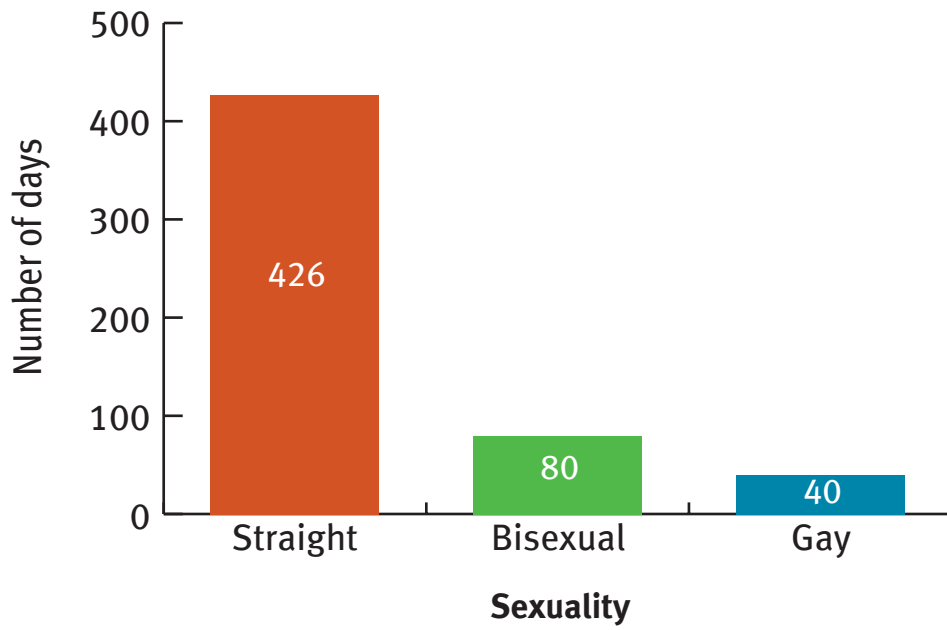
3. Who took part in A Day in the Life?

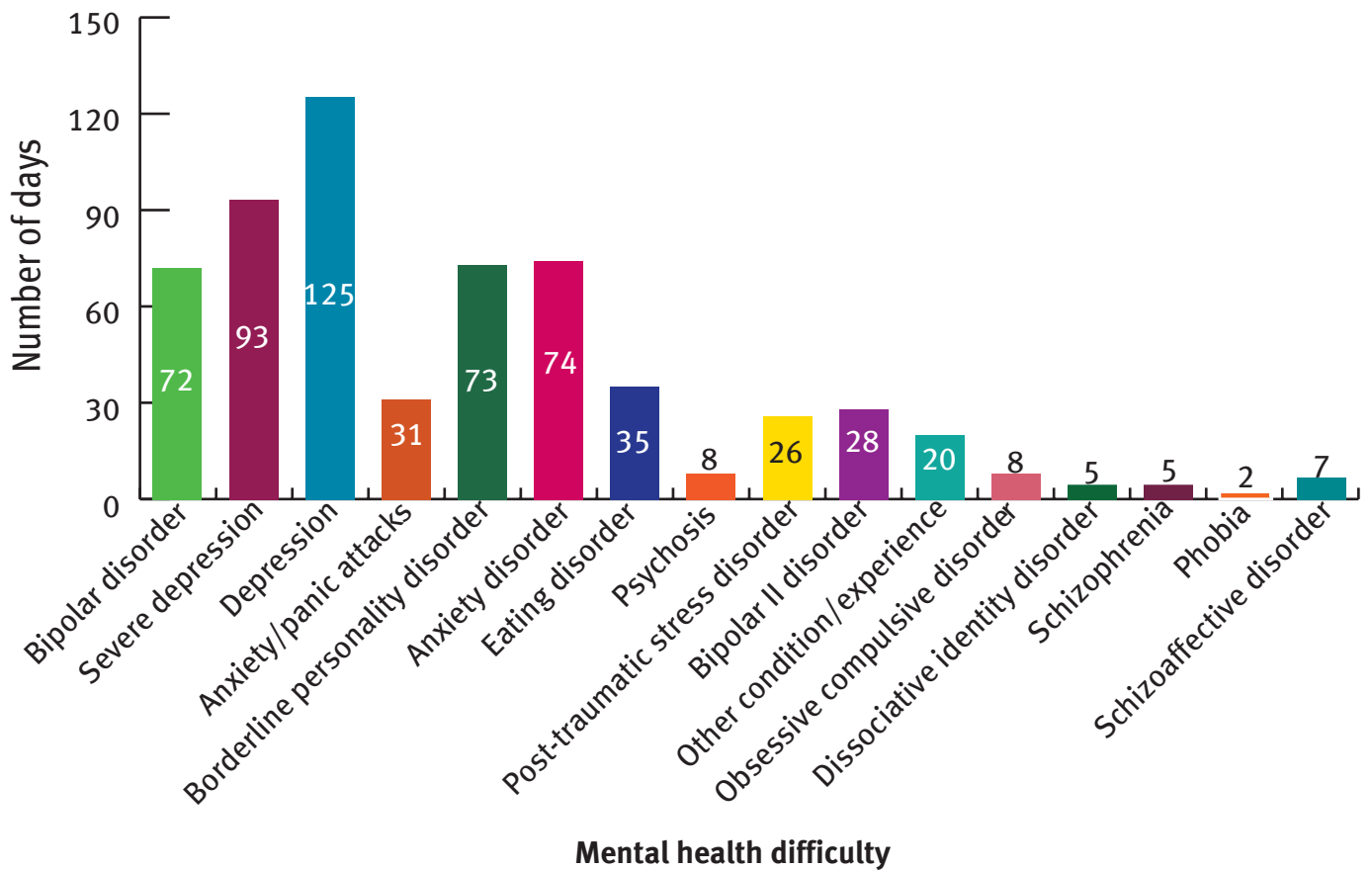
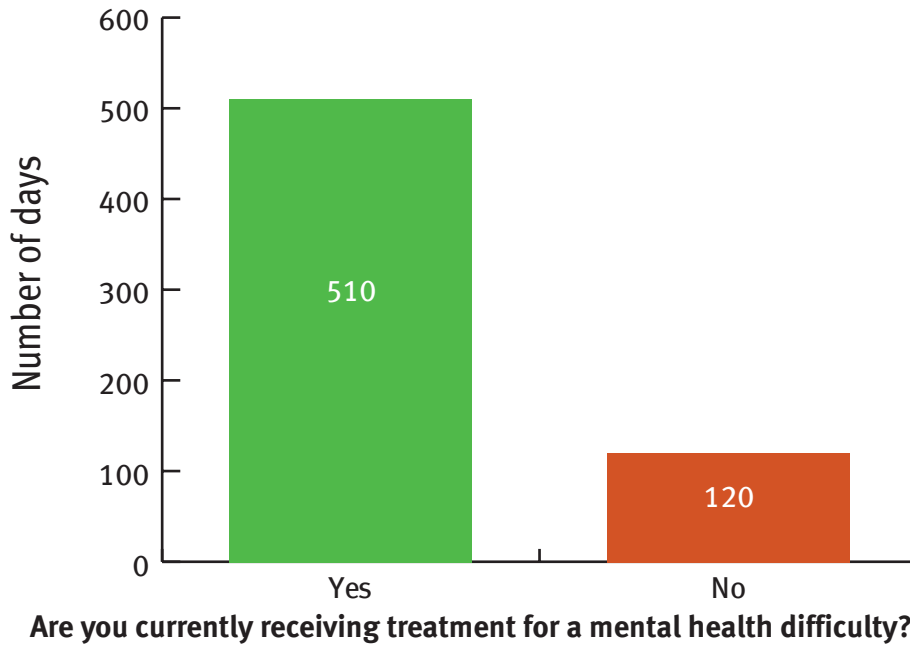
People taking part were asked to submit with each post some basic demographic data.

It was not mandatory for users to submit answers to these questions. The figures presented here relate to individual blogs rather than individual users; meaning that some people may have submitted four days while others may have submitted one, two or three.

The vast majority of participants described themselves as White British, with a small number not disclosing their ethnic heritage and negligible numbers from Black or minority ethnic backgrounds. This raises important questions for future exercises of this kind to ensure broader representation of the ethnic mix of the population.







4. The value of lived experience

A Day in the Life has demonstrated the value of using technology to crowdsource evidence which can inform research, policy and practice in relation to mental health. As a ‘proof of concept’ it shows that by asking people to write about their days, without direction, researchers, policymakers and commissioners can begin to understand the everyday lives of the people about whom they are concerned.

Services intended to help and support people who experience mental health difficulties are predominantly commissioned at local area level by clinical commissioning groups in conjunction with local authorities, with needs assessments and strategies set by health and wellbeing boards. While data may be available around prevalence, demographics or best practice, these are unlikely to form a picture ‘close enough to the ground’ to fully capture local variation, lived experience and preference. Available data might tell commissioners what has been happening, but they won’t reveal why it has been happening. Shifting to an intelligence-based commissioning model will require a deeper level of understanding if the maximum level of benefit is to be generated. The A Day in the Life approach will be able to assist in framing problems, challenges and opportunities from the perspective of those in need rather than those in charge of creating and commissioning services and interventions.

The approach generates a public-facing collection of first person, experience-based writing. This can be a valuable aid to public debate in itself. When analysed in ways similar to the approach we have taken in this report, it offers further insights to help policymakers, commissioners and service providers.

Our analysis of the data from the narrative accounts shows that it can identify lines of enquiry but that there are limits to what conclusions can be drawn. Crowdsourcing can be a valuable additional tool for research, policy development and service improvement. It should not be expected to give all the answers but it can offer unique and powerful insights direct from lived experience.

This approach has potential to be used to ‘surface’ potential areas for further enquiry, highlighting what we may not have thought to examine, especially in areas where the existing evidence base is scarce or where the conditions of people’s lives have changed significantly in recent years. From a public mental health perspective, the A Day in the Life approach is in the tradition of John Snow’s investigations into the Soho cholera outbreak¹; seeing a bigger picture from a series of unconnected accounts. As such it could be used as a tool to fire creativity and help to point out areas where existing best practice lags behind lived experiences of those it intends to help.

It could also prove useful in developing new hypotheses or ‘hunches’, using similar non-directional calls to action, derived from the analysis of a number of people’s direct experience to be checked and tested with established methods.

Future uses of this approach could include:

- To explore specific issues nationally either relating to a particular group within the population or an issue facing large numbers of people where evidence is under-developed;
- To provide insight in a local area into the experiences of people with mental health problems, for example as part of a joint strategic needs assessment;
- To explore in greater depth people’s experiences of a particular situation;
- To offer a longer-term picture of people’s lives, going beyond a single year to enable patterns over time to be identified.

¹ See <http://johnsnowbicentenary.lshtm.ac.uk/about-john-snow/> for more on John Snow

5. Analysis

A Day in the Life has been an experiment, a prototype of a new way of accessing and understanding the lives of people to generate insights for later study and exploration.

The remainder of this document sets out what we found about different groups of people submitting their experiences through a basic content analysis of the accounts of their days.

In most cases, the numbers involved are too small to be regarded as statistically significant findings or to draw clear conclusions. But they offer new insights into possible areas for future research.

The totals in this paper represent the total numbers of times two coders using a set of indicators (see Appendix 2), working independently of each other, agreed on an indicator as being present in an account.

Seasonal and weekly variations

In the development of A Day in the Life, one of the hunches we wanted to test was whether the level of wellbeing people experienced differed between seasons. In the event, it appears that the day of the week was a more significant determinant of the topics people covered than the season. Accounts from Sunday, 10 May, for example, included fewer mentions of mental health services or of work, but more than the others of hobbies.

Age

The total number of days analysed that specified age was 638 out of 782. Of the 55 people who were aged 18-21, the support of friends and a sense of purpose in life were the most widely mentioned positive indicators, while self-stigma was the most common negative influence.

Among the 182 people aged 22-30, home life was the most common positive indicator (20), followed by experiences of mental health services (18), the support of friends (18) and work (17). The most common negative experiences for this age group were of mental health services and hobbies (both 20 days).

Home life was also the most common positive indicator for people aged 31-40 (mentioned in 22 of 163 days), followed by the support of friends (20). Poor workplace understanding of mental health needs and poor physical health were the most widely mentioned negative indicators for this age group (17 days each).

Positive experiences of mental health services (mentioned in 17 of 133 days) and a sense of purpose in life (16) were the leading positive factors for writers aged 41-50, while work (15 days), mental health services and hobbies (both 14 days) were the most common negative factors.

The most frequently assigned positive wellbeing indicators among writers aged 51-60 were social media (7 of 78 days) therapies as self help (7), and home life (6). Experiences of mental health services, hobbies and physical health (7 days each) were the main negative factors.

Of the 28 days submitted by writers aged 61-70, the most frequently assigned positive wellbeing indicators were: the support of a partner (5 days); the support of friends (5) and home life (4). The most frequently assigned negative wellbeing indicator was poor or unsatisfying sleep (4 of 28 days).

These results provide no straightforward patterns about the experiences of different age groups. They suggest that it would be difficult, and potentially unhelpful, to draw assumptions about people's needs and preferences according to their age.

Gender

Data about gender was available for 630 of the 782 days we analysed, of which 476 were female and 139 male. The remaining 15 days were written by people who specified themselves non-binary.

The most commonly mentioned factors that made a positive contribution to female participants' wellbeing on the day in question were the support of friends (54 of 476 days);

the routines and comforts of life at home (53); actual experience of mental health services (51 days); having a sense of purpose in life (44); undertaking hobbies and activities for pleasure; comfort or fulfilment (40); the sense of contributing positively in their workplace (39) and the support of a partner (37).

Of the days submitted where the person identified themselves as male, the most commonly mentioned factors that made a positive contribution to the wellbeing of the writer were workplace contribution and the sense that it had been a good day at work (15 of 139 days); the positive effect of mental health medication (13); the support of friends (12); sense of purpose or that life has a point (12) and exercise (10).

Of the days submitted by people who identified themselves as female the most commonly mentioned factors that had a negative impact upon the wellbeing of the writer were experiences of mental health services on the day in question (50 of 476 days); being unable to undertake hobbies or to execute them satisfactorily (50); problems with sleep (35); work (28); and perceived social stigma about their condition i.e. what others would think (27).

Among men, the most commonly mentioned negative factors for wellbeing were work (11 of 139 days); physical health (10); poor or unsatisfying sleep (8); and hobbies (7).

Only three of the 139 days written by people identifying as male mentioned family support as a positive factor. Eight mentioned that writing the A Day in the Life blog had a positive effect on their wellbeing.

Ethnic Heritage

The total number of days that specified ethnic heritage was 775 out of 782.

Looking at the days that specified ethnic heritage, it is obvious that A Day in the Life's results are not representative of the ethnic make-up of England. Further work of this kind would need to address this issue to ensure that experiences from the full range of communities was represented appropriately.

Long term physical health conditions

We were able to identify whether the writers of 605 blogs did or did not have a long-term physical illness.

Of the 223 days submitted by a person who identified themselves as having long term physical as well as mental health difficulties, the factors most commonly mentioned as having a positive effect on the wellbeing of the writer in the day in question were the support of friends (22); experience of mental health services (21); hobbies (19); and the routines and pleasures of home life (18). By comparison, those without a long-term condition were more likely to mention work, exercise and hobbies.

The most commonly mentioned factors that had a negative impact on the wellbeing of people with long term physical health conditions were concerns about money (29); their physical health on the day in question (26); hobbies (24); experiences of mental health services (24) and poor or unsatisfying sleep (22). Those without were more likely to mention the negative effects of work and less likely to talk about the lack of money.

An odd and possibly anomalous result was that 72 of 223 days which specified the writer as having long term health conditions as well as mental health difficulties mentioned a sense of purpose in life positively, while none of the 382 days where the writer had mental health difficulties alone did so.

Currently receiving treatment for mental health difficulties

The total number of days analysed that specified whether or not they were written by someone currently receiving treatment for mental health difficulty was 630 out 782.

510 of the days submitted were written by someone who said they were currently receiving treatment for their mental health difficulties. The indicators most commonly assigned for contributing positively to their wellbeing on the day in question were the support of friends (59); experience of mental health services on the day in question (57); home life (55); a sense

of purpose (47); mental health medication (46); the sense of a good or productive day at work (41); the experience of hobbies for pleasure or for the relief of distress (40) and the support of a partner (38).

For writers who specified that they were not currently receiving treatment for their mental health difficulties, the top positive wellbeing factors mentioned were: hobbies (12 of 120); a sense of purpose (11); friend support (11); work (10); and home life (9).

The most commonly categorised negative indicators among people currently receiving treatment for their mental health difficulties were: inability to carry out or derive pleasure from hobbies (51 of 510 days); experience of mental health services (51); poor or disrupted sleep (37); and a negative work contribution to wellbeing (30).

For those not currently receiving treatment for their mental health difficulties, the most common negative factors were: mental health services (10 of 120 days); hobbies (10); poor or disrupted sleep (9); and work (9).

The negative factors were broadly similar for both groups; including experiences of mental health services, which were mentioned by 8.3% of those not receiving treatment and 10% of those who were. This suggests that it may be worth further examining people's experiences of accessing mental health services.

Place

We analysed the responses of people living in cities, towns and villages to see if any differences emerged between urban and rural areas. No significant patterns emerged from this analysis.

Interestingly, the days that specified that they were written by people in cities mentioned that the negative tone of the media affected their wellbeing in 11 of 224 days, a higher proportion than in the other areas.

Sexuality

The total number of days analysed that specified the sexuality of the person writing was 546 out of 782.

It is interesting to note that of the days that specified the sexuality of the writer, the number of days written by a person identifying as bisexual (80) was double that of days written by someone specifying their sexuality as gay (40). This may not equate with number of people taking part, as some individuals may have submitted multiple days while some only submitted one.

We have not analysed the positive and negative indicators for this category, although this would be of interest.

Main mental health difficulty

The total number of days analysed that specified the main mental health difficulty of the person writing was 612 out of 782.

Looking at the five largest condition categories:

Depression

Of the 125 days that specified they were written by someone who lived with depression, the most assigned positive wellbeing indicators in our analysis were: work (15); the support of friends (14); hobbies (13); and home life (12 of 125 days).

The most common negative wellbeing indicators were work (10); self stigma (9); and poor or unsatisfying sleep (9).

Severe depression

Of the 93 days that specified they were written by someone who lived with severe depression, the most assigned positive wellbeing indicators in our analysis were: the support of friends (11); home life (8); sense of purpose (7); and experience of mental health services (7).

The most widely assigned negative wellbeing indicators were work (11); experiences of mental health services (11); hobbies (11 days of 93); and poor or unsatisfying sleep (9).

Anxiety

Of the 74 days that specified they were written by someone who lived with an anxiety disorder, the most assigned positive wellbeing indicators in our analysis were the support of friends (8); the pleasures and routines of home life (7 of 74 days) therapies as self help (6 of 74 days); hobbies (6 of 74 days); and social media (6 of 74).

The most common negative wellbeing indicators in our analysis were work (7 days); self-stigma (6); and poor physical health (6).

Borderline personality disorder

Of the 73 days that specified they were written by someone who lived with borderline personality disorder, the most assigned positive wellbeing indicators in our analysis were mental health services (12); the support of friends (10); home life (8); partner support (7); and family support (7);

The most common negative wellbeing indicators in our analysis were experiences of mental health services (11 days); inability to access or take pleasure or comfort in hobbies (11); self-stigma (6) and poor or unsatisfying sleep (5). Mental health services were mentioned in a greater proportion of days for this group (32%) than for any other condition.

Bipolar disorder

Of the 72 days that specified they were written by someone who lived with bipolar disorder, the most assigned positive wellbeing indicators in our analysis were: sense of purpose in life (11) the positive effects of medication (10); drawing pleasure or comfort from hobbies (9); and the positive effects of work (8).

The most frequently assigned negative wellbeing indicators in our analysis were poor physical health (8 days) and poor or unsatisfying sleep (5).

6. Refining and improving A Day in the Life

The most immediate legacy of the A Day in the Life project is the individual days that have made it up. A Day in the Life has successfully placed never-before-seen accounts of the everyday lives of people experiencing mental health difficulties in the public domain.

But it also has value as the prototype for a new way of addressing a range of social challenges, using lived experience as a starting point. And by regarding A Day in the Life as an experiment and a proof of concept we have learned much about ways to improve the next iteration of the idea.

We have identified a number of improvements for future projects using this approach:

1. Greater investment in coding

The number of indicators positively assigned in the coding process was low because an indicator could only be assigned to a post when both coders agreed to it. As the process was not a simple binary categorisation, but a series of judgements against a broad set of indicators, coders inevitably had differing opinions. Our initial plan was to include an arbitration procedure for such disagreements with a third party reading each disputed post and casting a deciding vote. This step was not implemented due to budget restraints.

A similar outcome could have been achieved by employing a third coder to read and categorise all of the posts using the same methodology. This will be factored into future iterations of the concept.

2. Testing and standardisation of indicators

In this first prototype of the A Day in the Life process we did not have a chance to standardise and test our indicators. Ideally, we would have tested the coders on a number of trial posts to see how far their coding diverged from each other and then modified the indicators to reduce ambiguity.

Future iterations of this idea will require this stage to be undertaken in tandem with the development of the project as a whole.

3. Broad indicators vs. narrow indicators

In this first proof of concept for the A Day in the Life approach we were unsure as to what we would find. Aware that we only had the budget to do one sweep through the assembled days, our indicators were broad and numerous. This increased the burden on the coders and gave us very broad findings.

In future iterations of the idea, or future explorations of the current existing collection of submitted days, we would suggest a more narrow and focused set of indicators.

This could be achieved by choosing a more bounded initial question such as “how did you feel about college today?” or by choosing a tighter set of indicators on a particular theme. For example friendship might be a headline indicator beneath which a more detailed subset of indicators could be identified, such as: 'Did the written account mention friends positively? If so did it mention:

1. Seeing friends socially?
2. Asking friends for practical assistance?
3. Seeking emotional support from friends?
4. Contacting friends directly?
5. Contacting friends via social media?'

An area of enquiry or special interest could shape these indicators from commencement of a future project.

It is also possible in a future iteration that more specific data could be requested. This might include asking for a numerical score for how positive the person felt on the day in question or survey style questions such as ‘did you visit your local high street?’ or ‘are you currently claiming in work benefits?’.

A future iteration could align the requested demographic metadata about each contributor with indicators so that what the writer tells us about themselves can be better combined with what they mention in their submission.

We were also unable to draw any firm conclusions from the data about whether indicators correlate with one another – for

example, whether a sense of purpose is correlated with work or with hobbies.

4. Deployment of the process to a defined purpose

In the next iteration of the A Day in the Life idea, it may be sensible to sharpen the focus of the project. This could be achieved by narrowing the range of indicators used to interrogate the assembled narratives. Or a future project could target more pointedly particular groups of people, areas or situations. This could work well with people in a particular geographical location (say a local authority or CCG area) or with people who have a particular unifying factor in common. To do this at scale, it may be necessary to move away from the idea of limiting the project to particular calendar days.

Another alternative would be to return to the Mass Observation model¹ of signing up participants to create more regular contributions over an extended period of time.

5. Publicity and reputation is important

For future iterations of the A Day in the Life approach, longer lead times will be required before launch with a strong media presence to ensure that people in intended groups sign up, and to seek contributions from groups who were poorly represented in the original project. To achieve more representative samples it may be necessary to turn the writing of days into an activity or outreach project involving people who may not otherwise hear or see the call to action.

Ultimately, the project and any future iterations are only as strong as the goodwill that enables people to put the significant trust in the organisers necessary to share such intimate material with the public and with those who will use it to help to guide policy and practice.

Reciprocal trust and respect is vital and must be maintained at all costs.

¹ Mass Observation was a UK social research project founded in 1937 that stated its aim as producing 'an anthropology of ourselves' by recruiting observers and volunteers writers to study the everyday lives of people in Britain. Mass Observation was one of the inspirations for A Day in the Life. Read more about Mass Observation here: www.massobs.org.uk/about/history-of-mo

7. Conclusions

While mental health difficulties and the people who experience them have never had a higher profile in public discussion in the UK, it has not always been clear whether society's understanding of people with mental health difficulties as human beings with hopes, fears, desires and dreams has kept pace. High profile anti-stigma campaigns seeking to tackle negative attitudes to those experiencing mental distress have pushed mental health further into the public eye. But there has been little focus in public debate on what promotes the wellbeing of people with a mental health difficulty, or indeed that it is possible to do so except by preventing mental illness.

Measuring and understanding wellbeing involves two different approaches. Subjective or personal wellbeing asks people directly how they think and feel about their own wellbeing. The second dimension, Objective wellbeing, is based on assumptions about basic human needs and rights, including aspects such as adequate food, physical health, education and safety. In the life of the individual both sets of factors are in a constant dynamic interplay.

Against a background of challenging budget settlements, it has become clear that we must collectively find ways of helping people who experience mental health difficulties to have lives where it is possible to feel fulfilled, secure, supported, alive to new possibilities and able to resume old interests, relationships and activities that may have been interrupted by being unwell. Treatment is vital, and improvements in support and treatment are similarly of great importance, but that is not the total sum of life.

To date, the wellbeing of people who experience mental health difficulties has been an under-explored area in terms of policy and practice. Interactions between researchers and people who experience mental health difficulties have often centred around either service improvement, the development of treatments or the understanding of symptoms. The data we currently have about people with mental health difficulties is most often taken from

the perspective of service delivery. Where people are consulted or included, the terms of engagement are often restricted to the business in hand and leave little room for the conditions of everyday life to be explored. What has been missing to date is a sense of what everyday life with mental health difficulty is actually like.

The focus in the debate about the wellbeing of people who experience mental health difficulties has often centred upon the reduction or removal of symptoms, rather than the quality of life on an everyday level, whether lived with symptoms or not.

The growth in social media platforms and increasing internet usage has provided people with mental health difficulties far greater opportunity to bring their experiences, ideas, discomforts and problems to a wider public. People who live with mental health difficulties are talking to each other far more widely than ever before. The approach tested by A Day in the Life shows that it is possible to harness these conversations and to build something from them that has both intrinsic value as a record of lives lived, and wider value for commissioners and policy makers.

A Day in the Life, containing raw, unfiltered first-person experience contributes towards understanding what life with mental health difficulty feels like and what makes it more or less liveable.

It has shown that it is possible to harness modern technologies to create a repository of publicly-available qualitative accounts that capture the imaginations of readers and contributors. It is possible to offer a window into the lives of people with mental health difficulties to anyone with time to read and a connection to the internet.

We have also shown that if approached correctly, people with mental health difficulties are willing to share a lot of detailed and granular knowledge about their lives and experiences.

A Day in the Life will, we hope, provide a greater breadth and depth of empathy and fellow feeling for the everyday struggles, pleasures and reliefs of people experiencing mental health difficulties.

The archive of personal experiences submitted to the project will remain online indefinitely, providing a valuable resource for anyone wanting to broaden their understanding of what living with mental health difficulties is actually like and as a testimony to those who took part.

To read the full days contributed to the project by hundreds of people who experience mental health difficulties visit:

www.dayinthelifemh.org.uk

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- The twitter mental health community.

Appendix 1: Methodology

Data collection

The website for A Day in the Life was built by Neon Tribe and fulfilled the dual purpose of allowing users to create accounts and edit submissions of days while maintaining at all time control over the content they created and submitted.

The project was launched with a short feature on BBC One's Saturday breakfast show with support from Public Health England's media team. Social Spider also carried out social media activity. Prior to the first collection day people were encouraged to sign up to the site, creating a log-in. They were sent a welcome email and were then sent reminders and notes on how to write up their day, with a final reminder to formally announce the collection period open.

Each of the four days was a call to write only about the particular nominated day. Collection opened at 17.00 on the day in question and remaining open until 23.59 seven days later. During that time people could still sign up and could enter and edit their day as they chose up until the deadline. Posts were saved as drafts, with the user having to take a two step process to submit the post for the project. No drafts were included in the final collection.

After the first day in November, publicity of subsequent days was carried out through social media promotion, articles and personal speaking appearances from Social Spider staff and other contacts.

A youtube video was created to publicise the third collection day and the fourth was promoted by a Public Health England blog.

A twitter hashtag #adayinthelifeMH was used to unify discussion around the topic and to later pull together the uploaded days as they were published to the web sequentially.

After the collection period closed each quarter, each uploaded post was read and checked for libel and other legal contraventions and checked against the guidelines for uploading (see Appendix 3). It was then assigned a broad categorisation comprising a number of categories with positive, negative and neutral versions:

Health; Home Life; Money; People; Services; Stigma; Things we do; Where we live; Work.

It is possible to use these headings and their negative, neutral and positive conditions to navigate through the days published to the site. Each published day on the site indicates which of the calendar days across the year it was written about. Posts can have multiple categorisations.

This categorisation was done by eye for the purposes of publishing the submitted days and is separate from the content analysis carried out to derive insights from the totality of the posts submitted.

Analysis

A set of 31 indicators (Appendix 2) was developed against which the posts were coded. These indicators were developed from discussion of what kinds of experience A Day in the Life posts might contain and areas that might be of interest to people with mental health difficulties, the general public and to health and other professionals.

The indicators chosen were purposefully broad as we did not know exactly what the submitted days in aggregate would contain. As such, our current analysis is as much a mapping of the broad shape of the territory as it is an in-depth cartography of its valleys and peaks. They cannot, for example, look at the extent to which the recognised indicator was assigned relative importance by the person

writing. It can ‘see’ how many days mentioned a particular theme but cannot see how important to an individual that particular theme was in relation to others.

Two coders with experience of content analysis were employed for a total of 16 days each to read all of the days submitted and see which, if any, of the indicators could be found in the account of the day. The coders were not involved in the development of the indicators and they did not see any of the demographic information submitted with the posts or have access to the user names of the people who wrote them.

An indicator was only assigned where both coders were in accordance. Due to time constraints, the coding of 782 days was completed by both coders.

Appendix 2: Indicators

1. CODE A1: Work place understanding of the individual and their needs

Positive: The individual is able to tell work about their mental health difficulty. There is no bullying or negative consequences due to mental illness. The individual has written/feels as though their boss/people at work support them and understand their needs and this has positive impact on their wellbeing.

Negative: the individual has written down any work place discrimination. The individual feels that they are not supported at work and all of this has negatively impacted their wellbeing.

2. CODE A2: Work contribution

Positive: the individual has mentioned that work has positively impacted wellbeing.

Negative: the individual has mentioned that work has negatively impacted wellbeing.

3. CODE A3: Interview stress/application stress

Positive: people mention the interview or application process in a positive way and don’t think their mental health difficulty will alter their chances of getting a job. **Negative:** People mention or have written that they are worried about applying because 1) scared they will be rejected 2) if they do get rejected then they take it personally 3) unsure if they should state their mental health difficulty at the interview/in the application form.

4. CODE A4: Blog mentions being a student

Positive: They have written how being a student has impacted their wellbeing in a positive way.

Negative: They have written how being a student has impacted their wellbeing in a negative way.

5. CODE A5: Volunteering

Positive: The blog mentions volunteering as having a positive effect on mental health.

Negative: The blog mentions volunteering as having a negative effect on mental health.

6. CODE A6: Work Achievement

Positive: Mental health difficulty has not prevented what they wish to achieve at work.

Negative: Mental health difficulty has prevented what they wish to achieve at work.

7. CODE A7: Medication

Positive: On balance the individual sees it as a way to improve their health and believes it is improving their mental health. In the post it is evident that taking the medication has been positive to their overall wellbeing on that day.

Negative: In the post it is evident that taking the medication has been detrimental to their overall wellbeing on that day.

8. CODE A8: Socialising

Positive: The individual has mentioned how socialising has a positive effect on the individual's wellbeing.

Negative: The individual has written or suggested that socialising has a negative effect on their wellbeing.

9. CODE A9: Sleep

Positive: Likes sleeping, want to sleep, sleep is a getaway and this has been a positive impact on wellbeing.

Negative: Insomnia, unable to sleep, doesn't want to sleep, scared to sleep and this has a negative impact on wellbeing.

10. CODE A10: Hobbies/things to distract them

Positive: They carry out hobbies for fun.

Negative: They carry out hobbies because they want to distract themselves/take their mind off things.

11. CODE A11: Actual experience of mental health services

Positive: The blog indicates that the individual thinks their services are good i.e. therapist, acute hospital team, look forward to home care team coming over. This has positively impacted their wellbeing. Note these can be split into the following categories:

- a) Actual positive experience with GP
- b) Actual positive experience with therapist
- c) Actual positive experience with acute hospital team
- d) Actual positive experience with nurses
- e) Actual positive experience with Care team

Negative: The blog indicates that the individual does not think their services are good. i.e. services stopped/cut short/waiting lists/anger at services. Actual stigma from mental health services, waiting, therapy stopped abruptly/services stopped abruptly. This has had a negative impact on their wellbeing. Note these can be split into the following categories:

- a) Actual negative experience with GP
- b) Actual negative experience with therapist
- c) Actual negative experience with acute hospital team
- d) Actual negative experience with nurses
- e) Actual negative experience with care team

12. CODE A12: Perceived state about mental health services

Positive: The blog indicates that the individual has heard good things about mental health services from people etc. and wants to use services available. This has had positive impact on their wellbeing.

Negative: The blog indicates that the individual has heard bad things about mental health services from people and don't want to use services available. This has had a negative effect on their wellbeing.

13. CODE A13: Self-stigma

Positive: Limited, rarely says negative things about themselves, doesn't let m.h. define them.

Negative: Projects negative aspects about mental health on themselves i.e. "not being normal", feeling towards their own mental health is really negative.

14. CODE A14: Perceived stigma

Positive: They haven't actually experienced stigma but they also have not felt like they are being attacked.

Negative: They haven't actually experienced stigma but think/ believe they are experiencing it even if they may not be.

15. CODE A15: Actual stigma

Positive: Have never experienced stigma first hand.

Negative: Have experienced stigma first hand.

16. CODE A16: Partner support

Positive: They have mentioned that their partner supports them/is there for them and they have had positive reflections about their partner/positive interaction with partner. This has had a positive impact on their wellbeing.

Negative: They have mentioned that their partner doesn't understand or finds it difficult to constantly support them. This has had a negative impact on their wellbeing.

17. CODE A17: Friend support

Positive: They have written that they are able to talk to friends about mental health difficulties and have written positive reflections about friends and positive interactions with friends. This has had a positive impact on their wellbeing.

Negative: They have mentioned how lack of friend support has had a negative impact on their wellbeing. Friends no longer speak with them because of their mental health, unable to talk to them.

18. CODE A18: Family support

Positive: family are there for them, they have written positive reflections about their family and they have positive interactions with family and this has positively impacted their wellbeing.

Negative: Their family are not interested and they are unable to discuss mental health with them nor are they able to rely on them for support and this has negatively affected their wellbeing.

19. CODE A19: Social media

Positive: Social media has a positive impact on the individual's wellbeing and mental health.

Negative: Social media has a negative impact on the individual's wellbeing and mental health.

20. CODE A20: Overall tone of the media/state of the world/Sense of the world

Positive: The state of the world or the sense of the world does not seem to have an effect on their wellbeing.

Negative: The state of the world or the sense of the world does seem to have an effect on their wellbeing in a negative way.

21. CODE A21: Religion

Positive: Religious beliefs have a positive impact on wellbeing.

Negative: Religious beliefs have a positive impact on wellbeing.

Positive: Religious community have a positive impact on wellbeing.

Negative: Religious community have a negative impact on wellbeing.

22. CODE A22: Actively doing certain therapy techniques to feel better

Positive: The blog post has mentioned the individual actively uses a technique such a mindfulness or they do the homework that has been set. They talk about this in a positive way and that it positively influences their wellbeing.

Negative: The individual mentions that they attempted to use a technique or do homework that has been set. They mention how they don't think using these techniques or doing the homework helps and so they believe it effects their wellbeing in a negative way.

23. CODE A23: Physical Health

Positive: They have mentioned physical health in a positive way and it can be seen that it has a positive impact on their wellbeing.

Negative: They have mentioned that physical health has a negative impact on their wellbeing.

24. CODE A24: Exercise

Positive: They mention in their post how exercise improves their wellbeing.

Negative: They mention in their post how exercise doesn't improve their wellbeing.

25. CODE A25: Blogs

Positive: People said that blogging or writing down their day had a positive impact on their wellbeing.

Negative: People said that blogging or writing down their day did not really help or improve their wellbeing.

26. CODE A26: Home life: here we are referring to stability, security and routine.

Positive: The individual has mentioned their home life in a positive way and it seems to impact their wellbeing in a positive way.

Negative: Home life has been mentioned in a negative light and has had a detrimental effect on their mental health and wellbeing.

27. CODE A27: Money

Positive: Money is mentioned but not as a worry.

Negative: Money worries are mentioned in the post and this has negatively impacted their wellbeing.

28. CODE A28: Alcohol

Positive: Alcohol has been mentioned in a positive way i.e. drinking to socialise. It is seen to have a positive impact on their wellbeing.

Negative: Alcohol has been mentioned in a negative way, such as drinking to numb the pain and cope etc. They have acknowledged that it is bad for them and it is seen that it has negative impact on their wellbeing.

29. CODE A29: Interactions with state agencies such as benefit services

Positive: Interactions with state agencies have had a positive effect on the individual's wellbeing.

Negative: Interactions with state agencies have had a negative effect on the individual's wellbeing.

30. CODE A30: Where they live: civic amenities, shops

Positive: the area they live in has made their wellbeing better or has had a positive impact on it.

Negative: The area they live in has made their wellbeing worse or has a negative impact on it.

31. CODE A31: Sense of purpose

Positive: The individual feels that they have a sense of purpose and that has positively impacted their wellbeing.

Negative: The individual feels that they have no sense of purpose and it is detrimental to their wellbeing.

Appendix 3: Guidelines for uploading

The following appears on the A Day in the Life website (www.dayinthelifemh.org.uk) as guidance to users as to how they should approach writing their day.

Welcome.

This is your chance to tell the world what makes life with a mental health difficulty better and what makes it worse. Tell us what made you feel better about your life and what made your life more difficult.

Here's the things to remember when writing about your days:

- Please write about what happened to you on the day specified. We want everyone to be writing about the same days.
- Don't reveal personal details; either your own or other peoples. Avoid naming specific people, organisations or services. Use terms like 'my local hospital' or 'a nurse' rather than using specific names.
- If talking about people you know please do not include sensitive personal information about them. Don't name them or include information that enable others to identify them.
- Please remember that A Day in Life is intended for people of all ages, backgrounds and beliefs to read.
- Avoid identifying yourself and where you live. A town, city or area is fine but do not include details that would allow someone to work out your exact location.
- Remember that your day will be seen by anyone visiting the site; so don't include anything in your account of your day that you wouldn't want other people to know.
- You are under no pressure to publish your A Day in the Life entries under your own name and we would advise that you remain anonymous.
- Once you are happy with your day, press upload. Please be patient when waiting for notification of it being accepted.
- Remember: after you have submitted your day you will not be able to edit it. If there is a problem email mark@socialspider.com
- You can request for any of your days to be removed from public view on the site at any time, though they will still remain in the database until the end of the year.
- Any entries that include contents that contravene existing law (including the Equality Act 2010) will either be edited or refused publication.

A Day in the Life

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To find out more about Mark Brown or Social Spider CIC, email mark@socialspider.com or tweet [@markoneinfour](https://twitter.com/markoneinfour)

Photograph: istockphoto.com/ooyoo

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SocialSpider Centre for Mental Health

Mark Brown and Geena Saini

A Day in the Life

What happens when you ask people who live with mental health difficulties to write about their everyday life?

1. Introduction

A Day in the Life was a one-year crowdsourcing project conceived and carried out by Social Spider CIC that asked people living with mental health difficulties one very simple question: What was your day like? What made your mental health better and what made it worse?

On four calendar days between November 2014 and August 2015 via an open appeal, the project asked people who identified themselves as living with a mental health difficulty to write up to 700 words about what their day was like.

These accounts of ordinary days lived with mental health difficulties were then published on the internet, unedited at www.dayinthehell.org.uk for anyone to read. They represent the largest single collection of accounts of the everyday lives of people with mental health difficulties.

Over the year, 893 different days were written by participants, or nearly half a million words, giving a window into the everyday lives of people with mental health difficulties.

When people signed up to the project they were told: "We'll categorise your day based on what things you mention in your account. We are categorising entries for two reasons. Firstly, so that once uploaded it is easy for people reading to find days that feature experiences they are interested in; and secondly so that we will be able to put together simple reports talking about broad trends for interested readers based on all of the uploaded stories."

People taking part were encouraged to remain anonymous and not to give details that would make their account identifiable. They were also encouraged not to compromise the privacy of others and not to write about institutions or services by name. Participants were asked to specify broad demographic details with each post such as age, gender, type of place they lived, whether they had any other long term health difficulties and what they felt their primary mental health difficulty to be. This demographic information was optional. People may at any point withdraw their submitted work from the online archive at www.dayinthehell.org.uk, with funding from Public Health England, Centre for Mental Health and Social Spider CIC carried out a limited content analysis of 782 of the uploaded days seeing what, if anything, all of these days told us overall about what affects the day-to-day wellbeing of people living with mental health difficulties.

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