

Lincus Trial: YMCA Liverpool pilot study for individuals with multiple and complex needs

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INTRODUCTION

A Liverpool City region consortium, led by Plus Dane housing association (the Hub) is likely to receive funding from Big Lottery to utilise a variety of interventions on addressing the needs of those with multiple and complex needs at a risk of homelessness. Part of the requirement of the funding is that evaluation tools and methodologies are used to capture the impact of interventions on the target population (service users) and on the city ecosystem (system change). Rescon, a UK technology company, working in Liverpool, have developed a tool designed to capture the impact of interventions on individuals and their communities. They have co-developed this with YMCA Liverpool and the Hub. A pilot study was undertaken, as outlined below, to test the usefulness of the tool and its usability and tolerance by service users and service providers.

AIMS OF THE PILOT STUDY

The aims of the pilot were

- To assess the current usability of the Lincus system in allowing support workers to assess people with complex needs and record interventions or events for each person.
- To establish how effective the data recorded was in potentially measuring the effect of interventions or events.
- To progressively develop Lincus and create lessons learned for future developments.

SCOPE OF THE PILOT STUDY

12 YMCA members were identified as suitable for the pilot based on having a number of the five identified needs and a willingness to engage with the pilot. Of these two members had three of the identified needs, five members had four of the identified needs, and the remaining five members had five of the identified needs.

LINCUS

Lincus is a tool by which to survey populations. It enables users to record and visualise individuals' data, to store details of all significant events in their lives and any interventions that are performed to help them, and to capture their perception of their wellbeing with respect to different areas of interest.

The Lincus surveys use a number-free icon-based system. The user is encouraged to point to a level on a slider, between two extremes, to provide an answer to each question. The position of the slider is then translated into a numerical answer (between one and 10), but this is not displayed to the user. This is designed to prevent users becoming attaching significance to certain numerical levels for a question, which would bias future answers.

The Lincus interface is designed to be user-friendly and incorporates clear and specific icons to demonstrate what each question means where possible, so that translation is not required if users speak a different language (however, appropriate icons have not yet been fully developed to match the questions given in this version of Lincus).

The Lincus system consists of:

- 1) A secure website with a dashboard interface

This includes the following features:

- Case-workers can create accounts for other case-workers within the same organisation, and for service users.
- Wellbeing surveys can be performed online (Figure 1a shows a screenshot of one of these). If permitted access, service users can view enter their own data, or case-workers can do enter survey results for their users.
- All events that occur, and interventions performed by the organisation or others can be recorded.
- Individual user data can be viewed in a number of different formats (See Figure 2 shows an example).
- Survey results, and event/intervention data can be combined across all users, viewed and analysed (See Figure 3 for an example).
- It is possible to view individual users' data only if you have appropriate permission. Otherwise depersonalised, combined data is available in which no users are identified.
- Searches can be run to find instances of events or interventions, or to view and compare data over specific date ranges.

- 2) An application that runs on Android devices (phones or tablets).

This provides portable access to the surveys (see Figure 1b). The app establishes a secure connection to the website, checks the credentials of the case-worker, and then downloads the surveys relevant to the users that the case worker has permission to record. The case-worker is then able to take the tablet with him to record user data (the location of the app is recorded when data is taken) and upload it to the server at his convenience. The app is able to use the device's camera to take photos and tag them to certain events.

- 3) Security and Back-up

A secure database backend to store credentials and user data. Data is regularly checked for consistency and backed up. If collecting data using an app the data is stored on the device until it is confirmed that it has been received by the server. Data is securely transmitted between the device

and the website database. A privacy policy is in place to protect Lincus users' data. If data is taken by an intermediary (such as a case worker) then the user's ID must be checked before any data is taken.

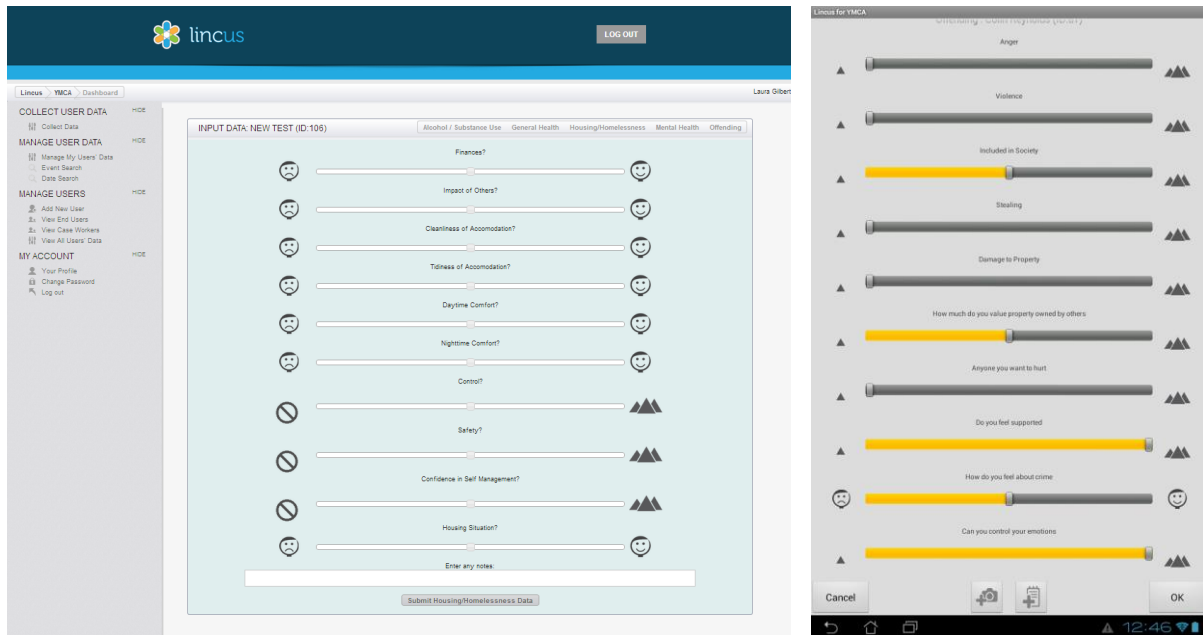


Figure 1: Survey tools. Figure 1a (left) shows an online survey (for a fictitious user) to record their experience of their housing situation. Figure 1b (right) shows a survey being used on an android tablet.



Figure 2: Viewing a user's data on the Lincus dashboard



Figure 3: Viewing data about interventions that have been performed

THE TRIAL

This Lincus trial was performed by the YMCA in Liverpool. 12 participants with complex needs, living in the YMCA, were surveyed every weekday for four weeks by two case-workers. There were five separate surveys, each of 10 questions, designed to query the participants' feelings on their situation. Table 1 details the questions asked within each of the five surveys.

Mental Health	Housing / Homelessness	General Health	Alcohol / Substance Use	Offending
Self Harm	Finances	Mood	How Often	Anger
Appetite	Impact of Others	Anxiety	Use for Feeling Better	Violence
Sleep	Cleanliness of Accommodation	Skin	Use for Calming Down	Included in Society?
Cleanliness	Tidiness of Accommodation	Abdominal Problems	Use for Feeling Normal	Stealing
Anger	Daytime Comfort	Pain	How easy is it to Stop?	Damage to Property
Anxiety / Stress	Night time Comfort	Cold / Hayfever	Alcohol	How much do you value property owned by others?
Clarity	Control	Cough	Pills / Powder	Anyone you want to hurt?
Mood	Safety	Sleep	Smoking	Do you feel supported?
Control of Self	Confidence in Self Management	Fatigue	Needles	How do you feel about crime?
Social Life	Housing Situation	Wellbeing	Solvents	Can you control your

emotions?

Table 1: List of questions contained in each of the five surveys.

Each question is answered on a scale of 0-10, where 10 is the most positive possible answer and 0 the most negative.

During this trial, in most cases each survey was performed only once a week, with a different survey done each weekday. (For normal operation of Lincus the case worker would expect to survey each user according to their needs – those with issues with drug/alcohol dependency would be surveyed more often in that area, and surveys would be performed at a frequency that is determined partly by the participant's needs and wishes.)

This trial was set up to determine Lincus' usability by organisations such as the YMCA. The case-workers used it to record a dataset which charts in detail participants wellbeing scores over time in different areas, and all events and interventions that occurred relating to each user. This data is discussed below in order to demonstrate some areas of Lincus' data visualisation and analysis capacity. The data throws up several hints of where future analysis should focus, as well as demonstrating the load on the case-workers over the month and detailing the resources spent on these residents of the YMCA.

All data discussed and visualised below is available within the Lincus system.

VIEWING INDIVIDUAL USER DATA

The Timeline

All events, interventions, notes, and photographs are gathered into one timeline (see Figure 4). This is an easy way to store and visualise the activities of the participant, and the work that has been done by case-workers in dealing with events and performing interventions.

In each case if the object is clicked then a popup will appear showing any notes or photographs taken on that day, or listing any events/interventions which occurred.

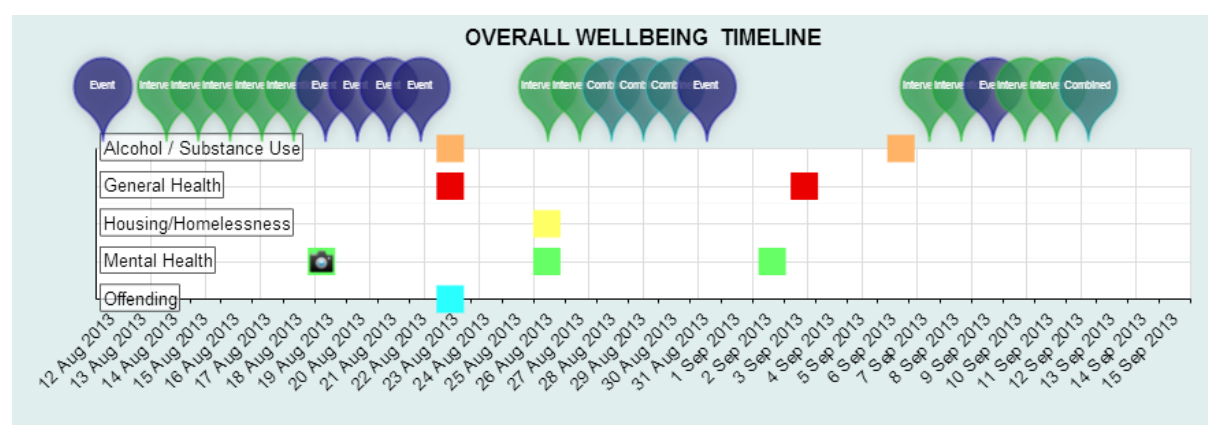


Figure 4: Example of a user Timeline, showing events and interventions in the bubbles along the top, and notes and photograph by category .A coloured square indicates that a note has been taken on that day, flagged by which category of wellbeing it is related to. A camera icon indicates that a photograph is available. A green bubble above the graph

indicates that one or more interventions took place that day, a navy bubble indicates one or more event, and a blue bubble shows that both events and interventions took place.

Wellbeing Scores

The user's data is shown for their overall wellbeing over time (Figure 5). Their wellbeing scores are also shown split up by category (Figure 6), and their answers to individual questions are displayed over time so that they, or their case worker, can track their progress in different areas (Figure 7).

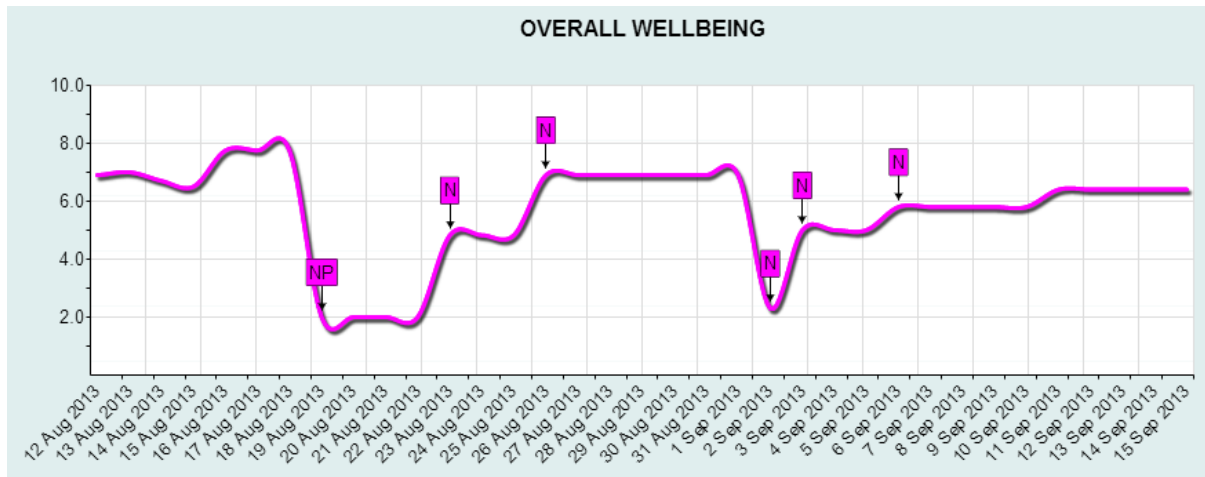


Figure 5: Example of an “Overall Wellbeing” chart, showing how the user’s perceived wellbeing changes over time. Days in which where notes and photographs are available to view are flagged.

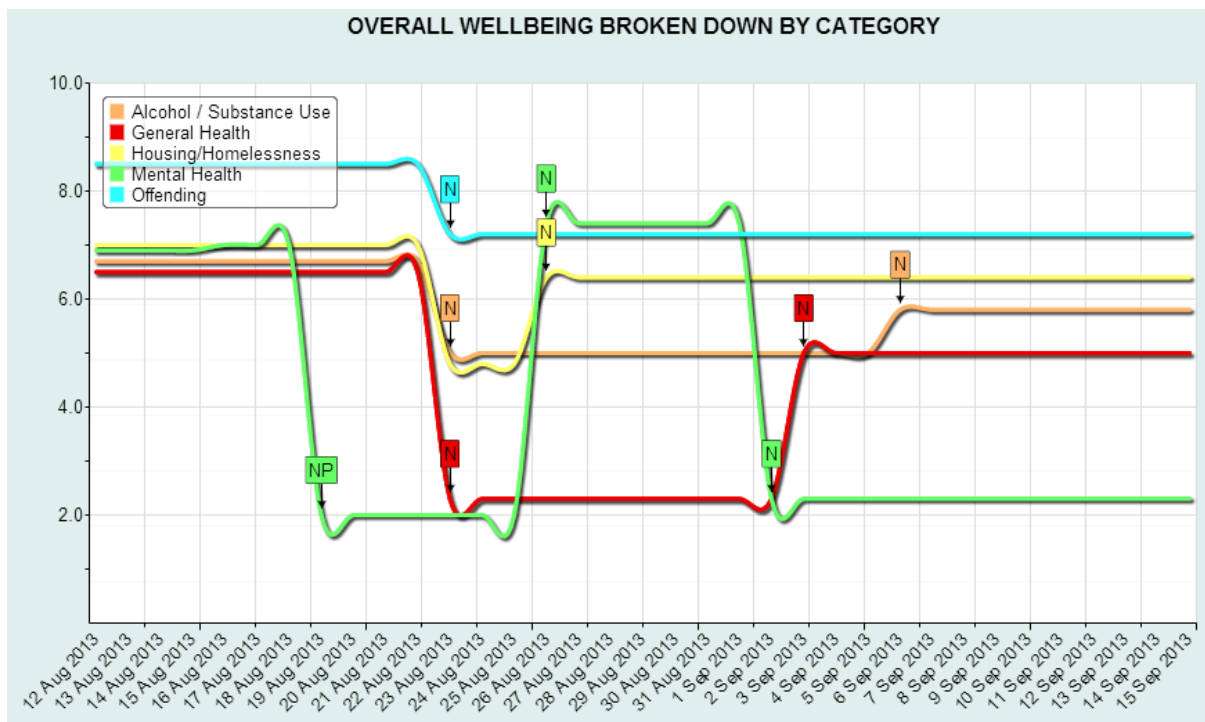


Figure 6: Example of a split “Overall Wellbeing” chart, showing how the user’s perceived wellbeing changes over time in different categories.

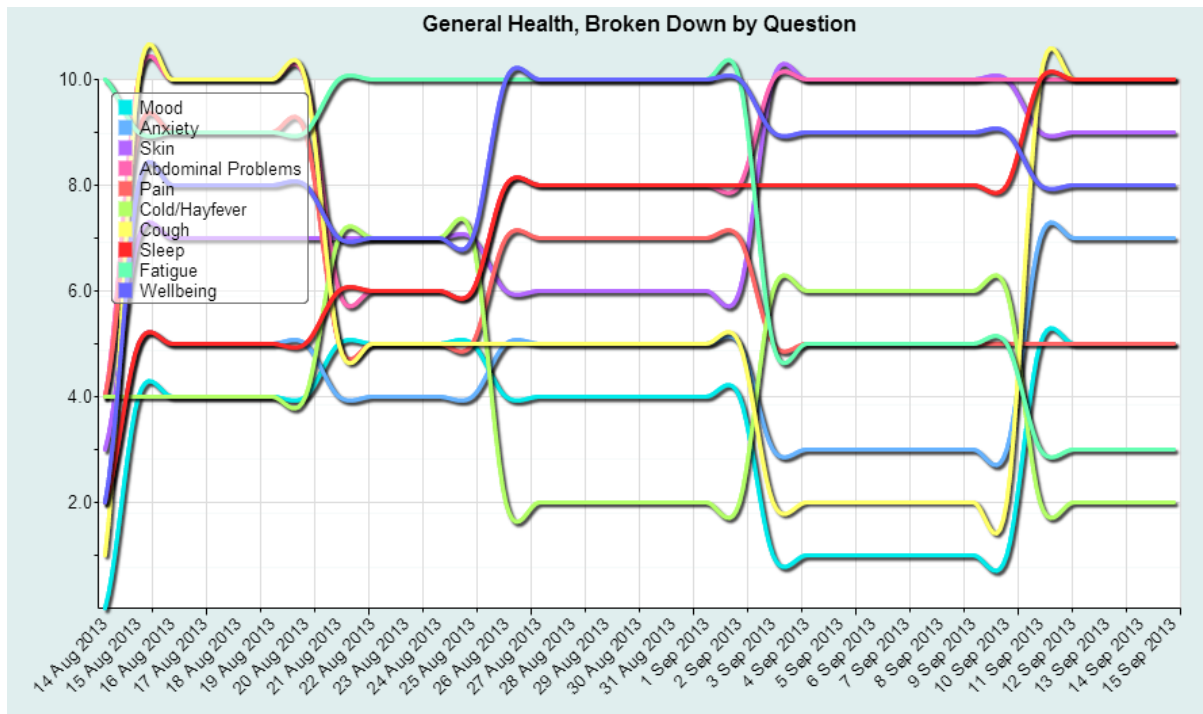


Figure 7: Example of display of how answers to the questions in a category change over time. This user answered questions on his general health once a week.

With Lincus users are empowered to track and monitor their own progress in different areas of wellbeing, and case-workers can easily record user history. Photographs can be taken and attached to data in order to record incidents as they occur. This provides a simple, but comprehensive and useful case history for individuals.

VIEWING COMBINED DATA

A powerful part of this system is that trends in the population as a whole, or selected sub-groups, can be recorded, analysed and compared. Events and Interactions data can also be counted and compared. Data shown below is combined data from all subjects over the course of the study.

Wellbeing data

The average wellbeing of participants over specified date ranges can be viewed and analysed. The average wellbeing of the group of participants over the course of the study is shown in the following charts. In general a significant improvement in perceived wellbeing is seen over the duration of the study.

1) Overall Wellbeing

The measure of overall wellbeing (straight average of all questions) exhibits a 13% improvement over the course of the study. This is based on an Ordinary Least Squares fit to the available data (Figure 8).

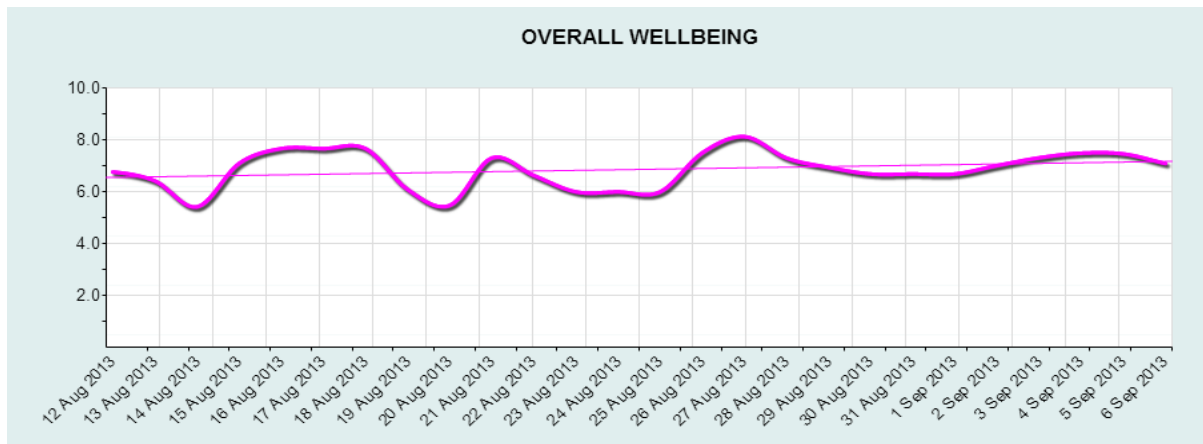


Figure 8: Average wellbeing scores of all participants throughout the study. The data is fitted with a smooth spline for ease of reading (thick line). An ordinary least squares line is fitted (thin line) to demonstrate the overall trend.

Figure 9 shows an overlay of the five separate categories of wellbeing, which are averaged to create the data shown in Figure 8. These are then plotted separately in the following five figures, and in each case a trend line is fitted to show whether each measure is improving or worsening over the course of the study.

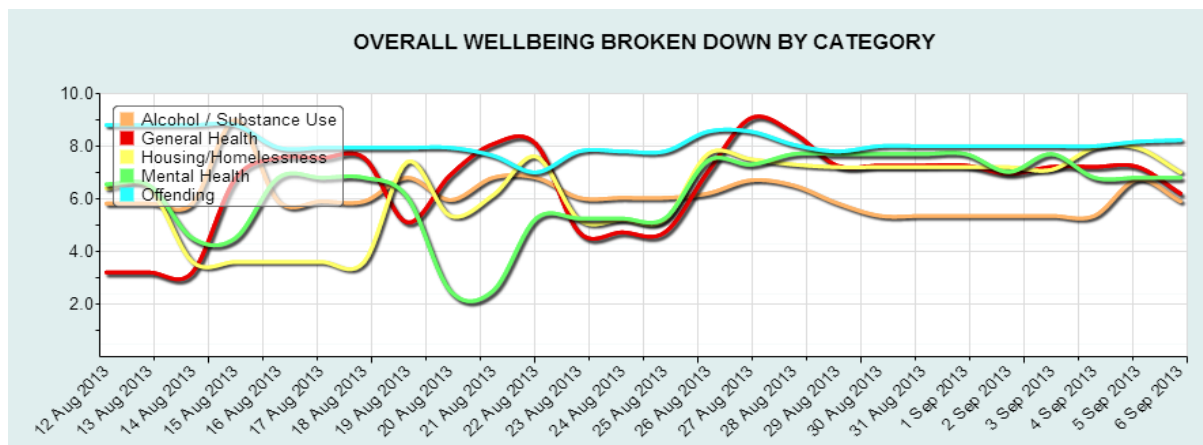


Figure 9: Average wellbeing scores of all participants throughout the study, broken down by category. The data is fitted with a smooth spline for ease of reading.

2) Housing/Homelessness

Figure 10 indicates that the subjects' perception of their housing situation improves by around 86% over the course of the study.



Figure 10: Average Housing and Homelessness Questionnaire scores of all participants throughout the study, broken down by category. The data is fitted with a smooth spline for ease of reading (thick line). An ordinary least squares line is fitted (thin line) to demonstrate the overall trend.

3) Mental Health

Figure 11 indicates that the subjects' perception of their mental health improves by around 52% over the course of the study.

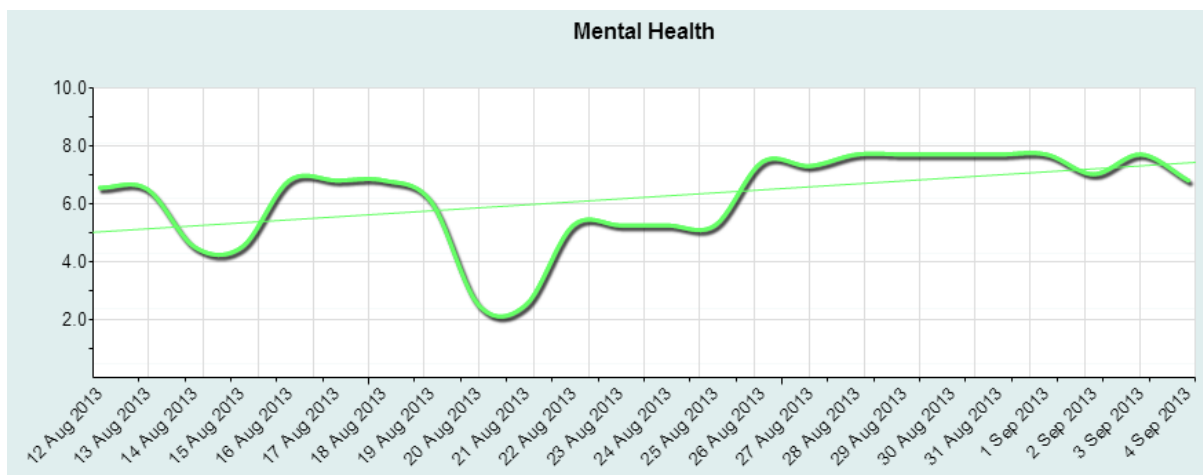


Figure 11: Average Mental Health Questionnaire scores of all participants throughout the study, broken down by category. The data is fitted with a smooth spline for ease of reading (thick line). An ordinary least squares line is fitted (thin line) to demonstrate the overall trend.

4) General Health

Figure 12 shows that subjects' perception of their overall health improves by around 23% over the course of the study.

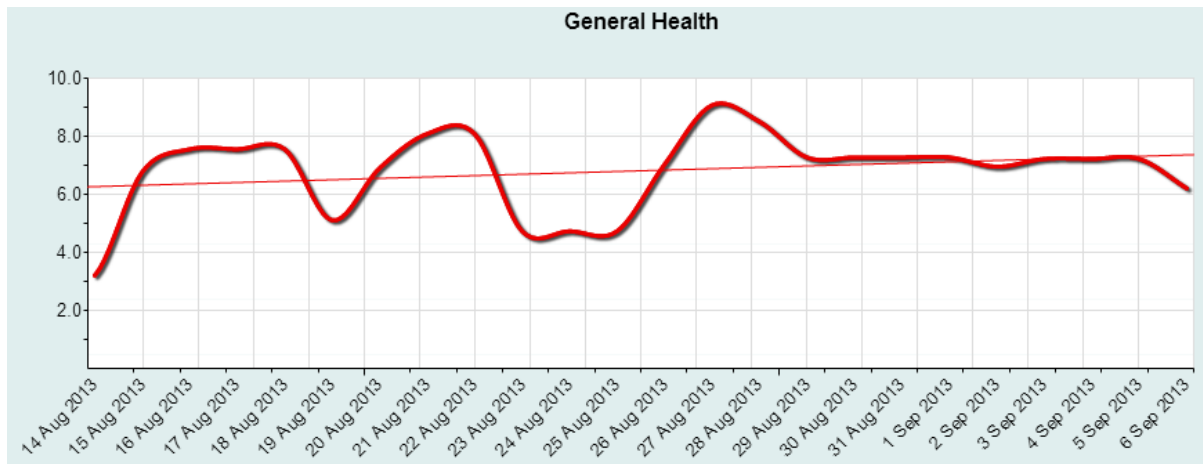


Figure 12: Average General Health Questionnaire scores of all participants throughout the study, broken down by category. The data is fitted with a smooth spline for ease of reading (thick line). An ordinary least squares line is fitted (thin line) to demonstrate the overall trend.

5) Offending

Offending: Figure 13 shows a negligible (2%) increase in offending – this is not statistically significant.

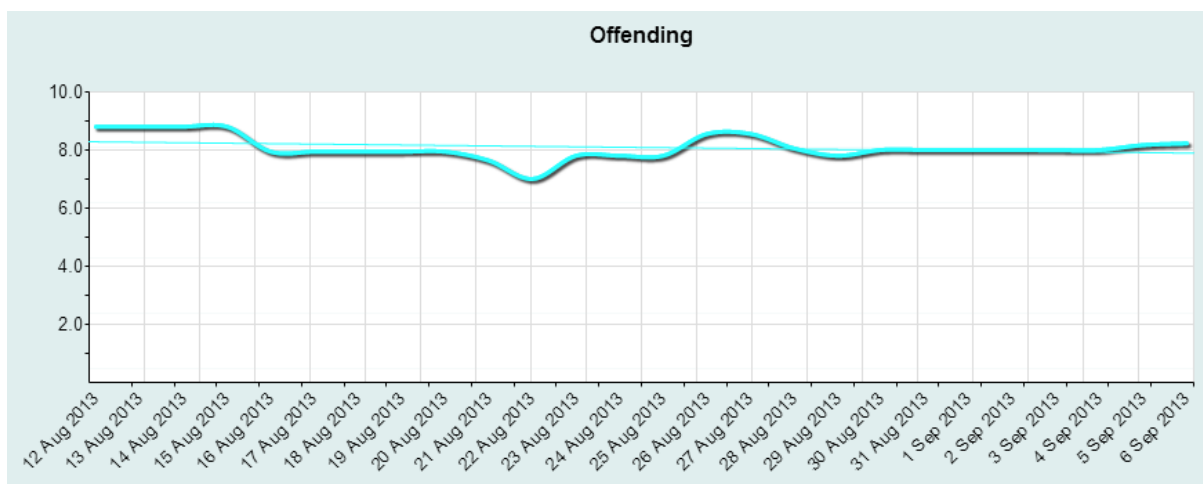


Figure 13: Average Offending Questionnaire scores of all participants throughout the study, broken down by category. The data is fitted with a smooth spline for ease of reading (thick line). An ordinary least squares line is fitted (thin line) to demonstrate the overall trend.

6) Alcohol/Substance Use

Looking at the trend line shown in Figure 14, alcohol/substance use appears to get worse by 17% over the course of the study. This appears to have been caused mainly by the very positive data recorded on the 15th August (if this data point is excluded then this measure is approximately flat over the course of the study). The data at the beginning of the study should be considered less reliable, since the case-workers and participants were only just beginning to use the system and learn how to identify and record their data.

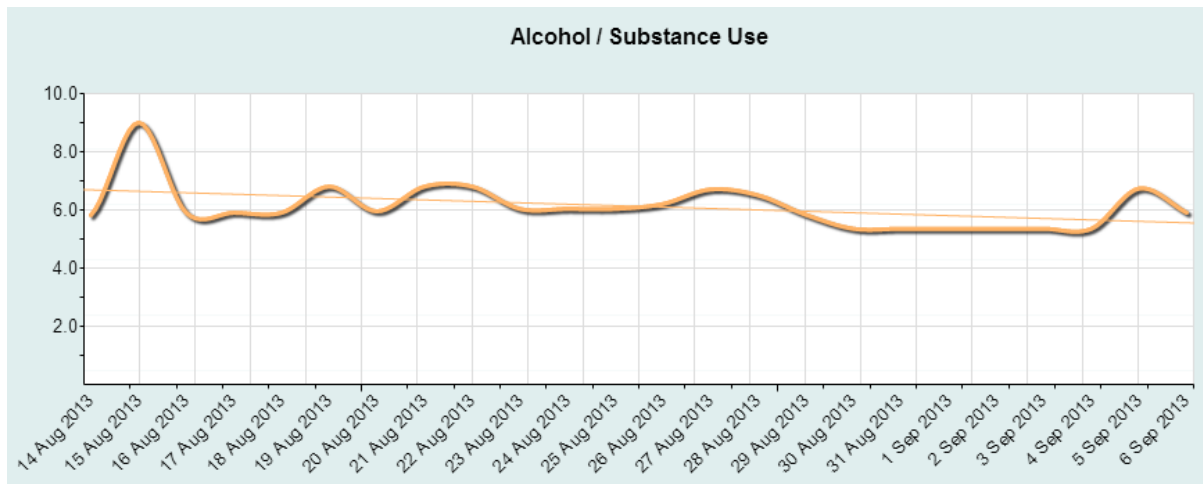


Figure 14: Average Alcohol and Substance Use Questionnaire scores of all participants throughout the study, broken down by category. The data is fitted with a smooth spline for ease of reading (thick line). An ordinary least squares line is fitted (thin line) to demonstrate the overall trend.

At present all questions are weighted equally when calculating overall wellbeing scores. It is likely that this is not the best measure of wellness, and a more detailed study should take place to decide relative weightings for each question. For example, when considering mental health it is possible that “mood” scores are a better indicator of mental health than “cleanliness” and that the relative weighting of the former should be greater than the latter when producing a combined score.

There are also a number of other ways to perform fits to the data to show trends that are more complex and show more information than a simple straight line fit. In future a range of fits will be made available to the user, to apply according to their needs.

Event/Intervention data

Data on interventions and events can be gathered and displayed. The effectiveness of various interactions between participants and support workers, and the effect of events on different areas of wellbeing can be viewed and studied. Because of the small size of the trial this data should not be used to draw firm conclusions about events and interventions, but it does provide some hints. Gathering more data would enable strong links to be made between events, interventions and participant wellbeing.

Events:

There were 97 registered events recorded over the period, of which around a quarter were related to antisocial behaviour, and another quarter to severe intoxication. 20% were reported “positive” events. Around 60% of the antisocial behaviour events were concentrated in week 2 and 40% of the severe intoxication (see Table 2).

Quick and easy access to this combined data enables managers to assess the load on their staff at any point in time, and measure whether it is increasing or decreasing under different circumstances. It will also enable people to analyse for trends – for example whether more of certain types of events occur at different times. For example - do more “severe intoxication” events occur

immediately after payday, and if so what can be done to improve the situation? Is there more property damage in autumn when the light levels are starting to drop?

Events	Entire Period	Week 1 (11-17 Aug)	Week 2 (18-24 Aug)	Week 3 (25-31 Aug)	Week 4 (1-7 Sept)
Antisocial Behaviour	26	5	16	4	1
Police Contact	6	2	0	4	0
A&E Admission	4	0	2	2	0
Unplanned GP/Hospital Visit	17	3	7	3	4
Property Damage	1	0	0	1	0
Legal Sanction	1	0	0	1	0
Severe Intoxication	24	3	9	6	6
Positive	18	4	8	3	3
Total	97	17	42	24	14

Table 2: Overall number of events of each type recorded over the course of the study, broken down by week.

Figure 15 compares the number of each type of event that occurred in the first and second halves of the trial. The number of antisocial behaviour events dropped by about three quarters from the first to the second half of the trial.

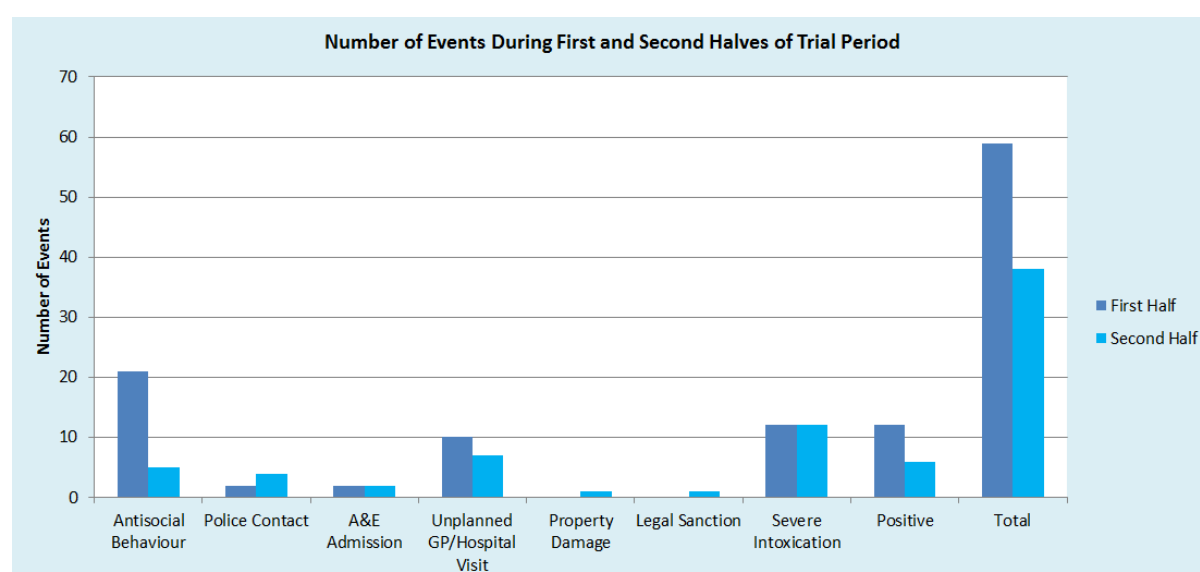


Figure 15: Overall number of events of each type recorded over the first and second halves of the study.

The data for different users can be sorted by event and combined to give an impression of how events/interventions of different types effect people's perception of their wellbeing. Again there is not enough data in this brief trial to draw meaningful conclusions, but an example is shown in Figures 16 and 17. In this case a search was performed over all "severe intoxication" events. For each event the wellbeing scores on the day of the event are averaged across all users, and this day is labelled Day 0 on the x axis (regardless of the actual date). The day after is Day 1, the day before the event is Day -1 and so forth. In this way a picture can be built up of wellbeing scores before and after a certain event.

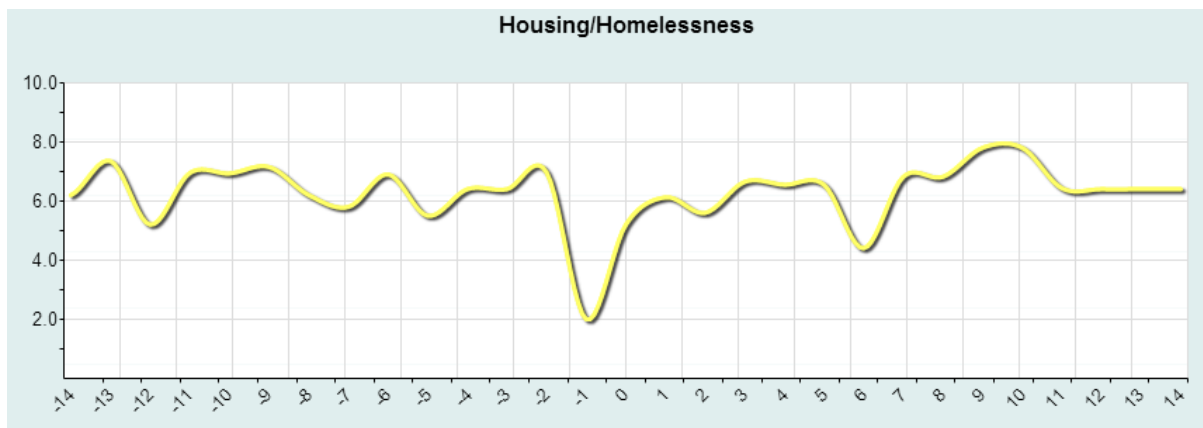


Figure 16: Averaged Housing and Homelessness scores in the fortnight leading up to, and following, a severe intoxication event. The date of the event is marked 0 on the x axis, 1 indicates the day after the event, -1 the day before and so forth.

Figure 16 hints that often a severe intoxication event (at 0) immediately follows a very low Housing and Homelessness score (it is about 2/10 the day before such an event, compared with the average score of 6/10) suggesting that a person feeling very negative about their housing situation is perhaps more likely to get very drunk. Again there is not enough data to draw statistically meaningful conclusions, but a longer running study would be able to produce clearer results that could be used by case-workers – for example (hypothetically) if the above was supported by more data, then a case worker might spot a dropping satisfaction with housing and homelessness, realise that this is often followed by severe intoxication and effect an intervention.

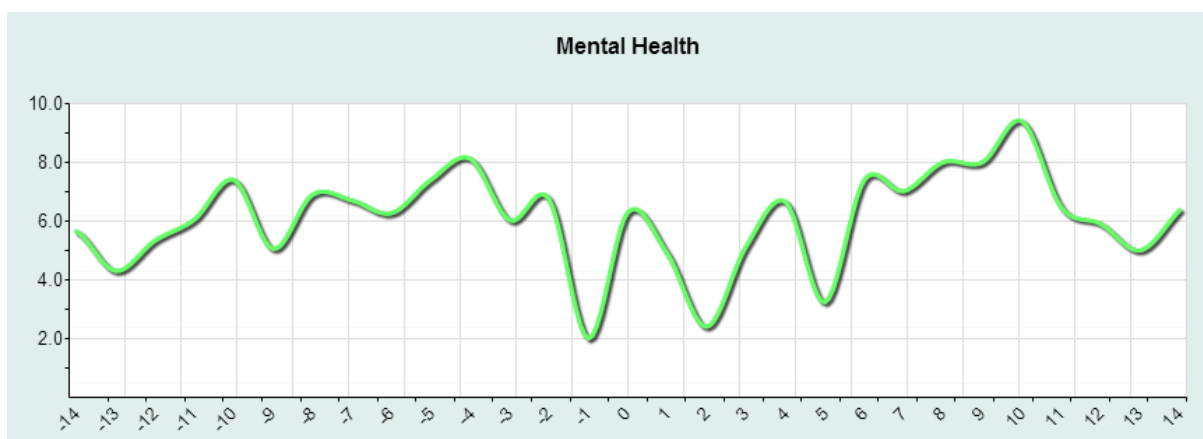


Figure 17: Averaged Mental Health scores in the fortnight leading up to, and following, a severe intoxication event. The date of the event is marked 0 on the x axis, 1 indicates the day after the event, -1 the day before and so forth.

Figure 17 shows the effects of the same intoxication events on mental health. Again the event (at 0) appears to follow a day in which mental health scores are worryingly low (day -1). On the day before these sorts of events the average mental health score is around 2/10, compared to the average of around 6/10. The day of the binge itself the participants in general feel “normal”, and sit around the average score for mental-health (or they are not reporting accurate scores due to intoxication!). For the rest of the week the mental health scores are very labile, showing large fluctuations down into the lower part of the graph and back into the normal range. This variability may be a direct effect of the severe intoxication event, or it may be a result of low statistics - but it is likely to be affected by the fact that often several such events appear in close proximity for such participants, so one severe

intoxication event is often closely followed by another, and then another. By day 10, in general, participants are experiencing a very positive feeling about their mental health (scoring 9/10), and after this the scores settle back into the normal range.

With a longer trial, including a greater number of participants, many meaningful connections between interventions, events, and wellbeing scores are expected to arise.

Going forward, filtering will be offered so that events can be compared based on their time of year, day of week or time of month, for example. It could also be possible to include searches to find events days with similar pollen counts or temperatures, or even days on which the local football team is playing.

It will also be possible to search for a chain of events to compare, for example, the wellbeing scores of people who had a support session following a severe intoxication event with those who did not, over the days and weeks that follow. This could be a very powerful tool with which to demonstrate to users the effects of their actions on their own mental health, for example, and also enable service providers to assess the effectiveness of interventions under a range of circumstances.

Interventions: There were 127 interventions recorded over the period, of which 68 were internal. Around 40% of these internal events were concentrated in week 2 (see Table 3), which corresponds with the elevated number of events in this week (see Table 2).

Interventions	Entire Period	Week 1 (11-17 Aug)	Week 2 (18-24 Aug)	Week 3 (25-31 Aug)	Week 4 (1-7 Sept)
Internal	66	18	25	12	11
External	13	4	3	2	4
Scheduled Visit	20	11	4	1	4
Support Session	28	9	2	6	11
Total	127	42	34	21	30

Table 3: Overall number of interventions of each type performed over the course of the study, broken down by week.

The number of internal interventions halved between the first and second halves of the study, whilst the number of support sessions rose (see Table 3 and Figure 18).

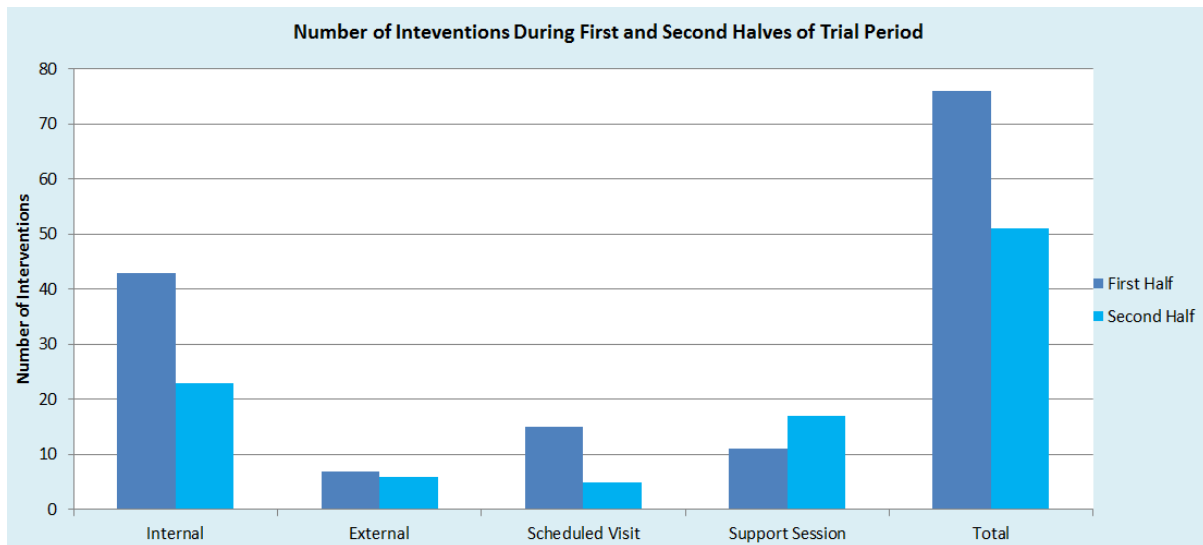


Figure 18: Overall number of interventions of each type performed over the first and second halves of the study.

Feedback from the case-workers suggests that the participants felt more “listened to” as a result of participating in the Lincus trial. This may have resulted in fewer reactive internal interventions being required as the participants felt more in control and happier with their housing situation (see Figure 10).

Because the case-workers were meeting the participants on a regular basis to discuss their views and circumstances, they may have also scheduled more support sessions as a result of issues arising, and this extra support in the form of “talking therapy” may have resulted in the improvements seen in mental health scores (see Figure 11). It is possible that this led to the reduction in antisocial behaviour in the second half of the trial.

It is indicated by this data that participating in the Lincus trial itself, and the actions of the case-workers in implementing the trial, may have had a positive effect on the participants’ overall wellbeing (as was hinted in Figure 8).

It is possible to use Lincus to directly assess the effects of interventions on wellbeing, but again care should be taken before drawing conclusions from this Lincus test data. This is for two reasons:

The short sample time and limited number of participants means that there is often not enough data from which to draw

The interventions themselves are not sufficiently well specified – for example “Internal” interventions cover a wide range of efforts, which would be expected to show different effects over different timescales. If the classes of intervention were more granular we would expect to be able to pick out the effects of different types of intervention more clearly.

Figure 19 shows the mental health profile of participants in the fortnight before and after an External Activity (such as a visit from an external professional body, inclusion in a detox program). The three days following the event show a marked drop in mental health scores, from the normal level of roughly 6/10, down to 2/10, before mental health recovers at day 4 (on average). This suggests that the immediate effects of an external intervention might have a short-term negative

effect on the person's mental health (perhaps starting on a methodone program is depressing!). More data would be required to show whether the longer-term effects of such interventions are positive.

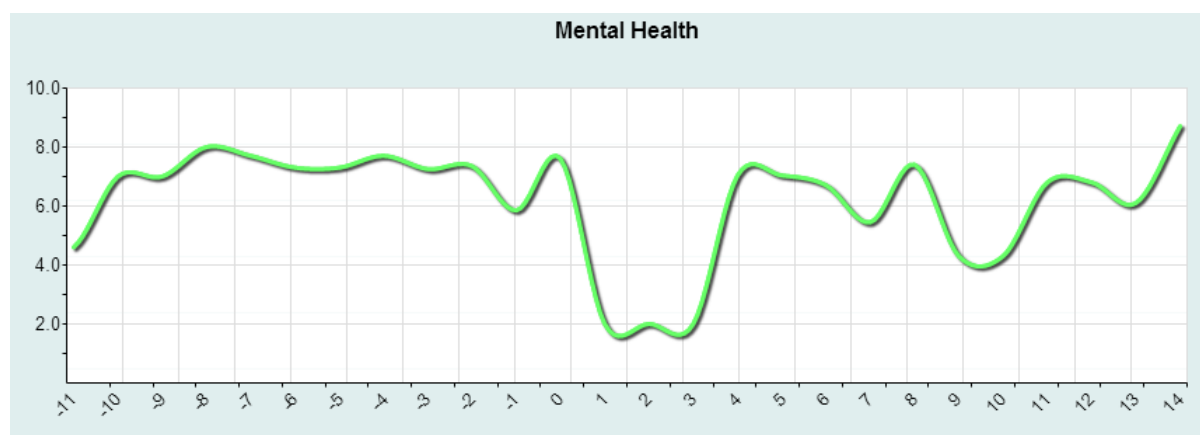


Figure 19: Averaged Mental Health scores in the fortnight leading up to, and following, an External Activity intervention.
The date of the event is marked 0 on the x axis, 1 indicates the day after the event, -1 the day before and so forth.

CONCLUSIONS AND LEARNING POINTS

The Lincus trial ran smoothly. No data was lost and the case-workers testing it found the system fairly intuitive and easy to use.

Support Workers and Lincus were been in regular contact during the pilot to identify any problems in the recording and display of information. Both workers found it easy to record and upload the information via the laptop and android application. The length of the assessment has been greater than anticipated with the average length of the assessment being between 5-7 minutes.

The trial produced useful data that could be easily viewed and analysed. It suggests that wider use of this system would produce data that would be very useful to the organisations involved, tracking and providing statistics on the histories of their service users and also their own actions when working with them. It also enables organisations to identify trends and measure how well interventions work in improving service user wellbeing over different time frames

The effect of participating in Lincus itself appears to have had a measurably positive effect on the population involved, as measured by improving wellbeing scores in almost all areas.

The trial made it apparent that it is very important that case-workers have clarity on how to phrase the questions to be clear but non-directional, and to guide the users towards indicating their answer on a slider and away from trying to give numerical answers ("6/10"). The case-workers who trialed this system are now in a good position to provide advice and training to other case-workers in how to perform the surveys to best effect.

Some service users became very involved in the process of collecting data about themselves and gained enjoyment from the process. These users were keen to be surveyed more regularly. Other users would have preferred to be left alone for longer between surveys. The frequency of surveying

should thus be guided in part by the users. Case-workers can still enter event and intervention data for these users as a way to track their case history even if their wellbeing data is sparse.

Some surveys are more relevant to certain users than others. There is no requirement for every user to take every survey with equal frequency – for a user having trouble with alcohol it would be informative to track that aspect of their wellbeing more often, especially before and after events and interventions. Very long gaps between measurements, however, can lead to spurious results appearing in the combined data and that should be avoided.

It will be important to clarify precisely which questions should be asked (for example it might be beneficial to separate alcohol from other drugs as they can have markedly different effects on behaviour).

It is also very important to decide which events and interventions need different categories. If there are too many categories the data for each will be too sparse to be useful, but if there are too few it becomes difficult to find meaning in the data. Interventions could be divided into categories according to the level at which the intervention is performed (e.g. Big Lottery Interventions, Service Level Interventions, and Care and Support Interventions). “Pay Day” for benefits should also be recorded as a separate event.

It may be beneficial to apply weightings to data during or after events. For example, someone who is intoxicated may give inaccurate answers (often over-reporting their wellbeing) and so their wellbeing in this period should be down-weighted in the combined data analyses.

Additionally, more informative wellbeing scores could be gained by weighting the answers to each question by the significance of the question. A working group of experts should be set up to clarify these parameters.

Support workers could be given access to the actual numerical scores produced in order to check that the numbers correspond with their expectations, check that their interpretation of the questions is accurate, and compare with the charts produced.

FURTHER WORK

Continuing technical work on Lincus includes:

- Addition of more complex comparison and analysis tools for user data, studying and identifying correlations between events, interventions and user sentiment.
- Addition of more complex comparison and analysis tools for studying work done by organisations in dealing with events and providing interventions.
- Presenting GPS data from mobile apps. Users who move around the city between locations could be surveyed at different centres at different times. Visualise the movements of users according to where they are surveyed.