One Precious Life: Technology Report

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CONTENTS

1 INTRODUCTION

The technology aspect of the One Precious Life project incorporats three main features. The first is a broad set of updates to Rescon's Lincus platform, making it more accessible to members of the general public and adding a number of features. The second is the provision of a vehicle (known as the Info Hub) by which to serve a number of health and wellbeing articles, as well as providing access to relevant ebooks, in a friendly and accessible format. The third is the development of an Android application which connected to a wrist tracker (OPAL). The wrist tracker was worn by participants, and the app enabled the automatic upload of pedometer data from the tracker to the Lincus website where the data could be incorporated with other wellbeing data.

Not all features mentioned in this document were funded directly by the One Precious Life project InnovateUK funding, but the project inspired all or significant parts of the work detailed here, such as the graphics icon and interface creation work (that was funded internally by Rescon).

2 PRIOR TECHNOLOGY

2.1 Lincus

2.1.1 Background to Lincus

Lincus originated in work to develop applications to improve the lifestyle of individuals with Type II diabetes for the US Department of Veterans' Affairs in 2010. The concept was later applied to medical history, and Rescon's Symptom-Tracker invention was registered with the US patent office in January 2011. The first incarnation of Lincus was developed throughout 2011, and it was presented at the NATO data visualisation working group in Vancouver in December 2011.

Rescon joined the Technology Strategy Board funded Mi Dallas consortium in June 2012 and Lincus was further developed in collaboration with the Liverpool Clinical Commissioning Group, local government, industry and third sector partners to stratify risk in a more dynamic way than the current two-year epoch stratification models.

A pilot of Lincus was commissioned by the Liverpool City Council to assess usability of the tool to assess the impact of interventions with the Liverpool YMCA in late 2012. The document "Lincus Trial: YMCA Liverpool pilot study for individuals with multiple and complex needs" (available upon request) showcases the results and conclusions of this trial. The success of this pilot resulted in Lincus gaining recognition by the National Institute of Clinical Excellence (NICE) as a tool for behavioural change in 2013.

Lincus became a foundation technology for Rescon's successful Long Term Care Revolution project, One Precious Life. Hft, the learning disabilities charity, also commissioned a highly successful pilot for the use of Lincus in individuals with learning disabilities in 2014. The document "Lincus: A Pilot Study on Individuals with Learning Difficulties" (also available upon request) documents the outcomes of this pilot. As a result of using this platform, staff at Hft were able to identify new conditions in service users, they reported better engagement with their clients. Rescon continues to engage with third sector and NHS collaborators for the ongoing development and deployment of Lincus.

2.1.2 Organisational Structure and User Groups

Lincus was built with a number of different user levels with different permissions, to be compatible for use within organisations. The basic set of user groups is as follows:

An overall ***administrator*** can add and manage individual centres/organisations, and search and view depersonalised, combined data. They can add and manage individual users such as centre managers, case workers and end users. They can view and compare performance data for different centres. They cannot view individual end users' case histories and data.

A ***centre manager*** can add and manage case workers within their own organisation, and assign them to end users' cases. They can view end user data if the organisation requests that they do. They can

view combined depersonalised data for their own organisation, and summarise their own centre's records of events and interventions in a variety of cross sections. They can view and compare performance data for case workers.

Case workers / Support Workers can view and edit all data of users which are assigned to them. Their user ID is recorded when they store data on behalf of end users. They can view combined, depersonalised data for groups of users.

End users can view and enter their own data, including notes. They can view combined, depersonalised data for other users within the same demographic (a range of demographics can be selected).

2.1.3 Surveys and Visualisation of User Data

Lincus incorporates a number-free, icon-based survey tool by which to survey populations, which can be accessed via a web browser or smartphone. 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 interface is designed to be user-friendly and incorporates clear and specific icons to demonstrate what each question means where possible. Lincus stores data securely and privately.

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. Organisations are able to select the types of surveys that they wish their users to take, and Lincus support staff work with organisations to design additional surveys with appropriate icon sets where required.

Figure 1 shows the YMCA surveying interfaces and Figure 2 the Hft version. The surveys provided for different organisations are designed with their end user groups in mind. The YMCA surveys are designed for people with multiple and complex needs at risk of homelessness, therefore there is a "Housing and Homelessness" survey alongside surveys to chart general and mental health, relationship with drugs and alcohol, and offending. The Hft surveys, targeted at a population with learning disabilities, were designed to appear very friendly and easy to understand. They also include an accessibility view by which users can answer questions one at a time, instead of accessing all questions of a survey on the same page. The Hft surveys are also shorter: most Lincus surveys are ten questions long, whereas the Hft surveys are four or five.

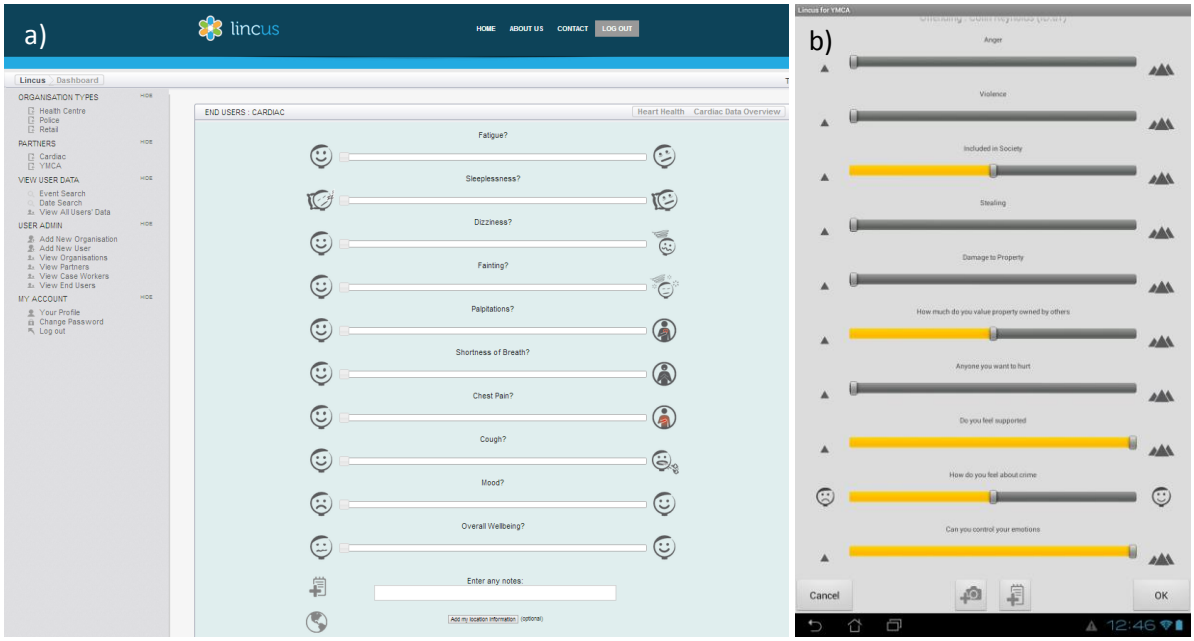
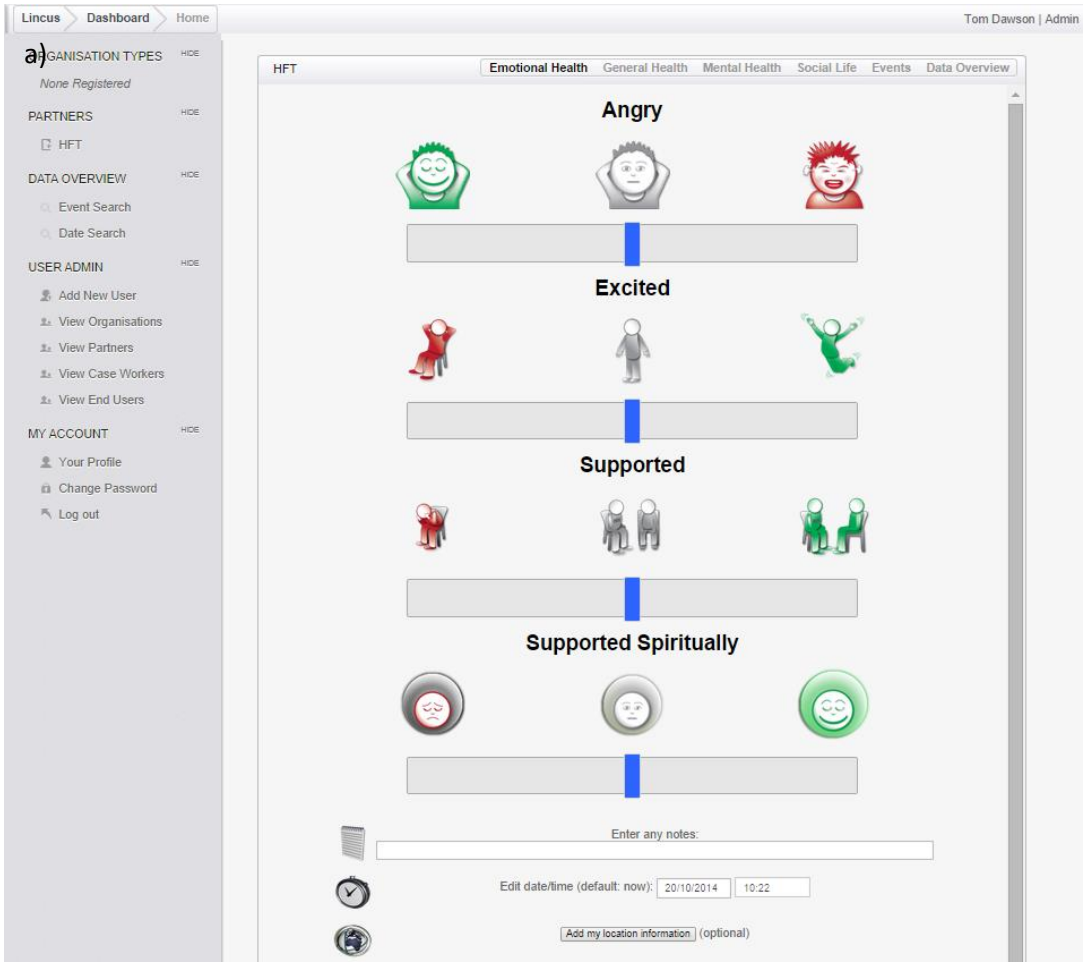


Figure 1: Survey tools for YMCA. a) shows an online survey for a YMCA user to record their experience of their housing situation (Administrator view). b) shows a survey on an android tablet, on a bespoke app.



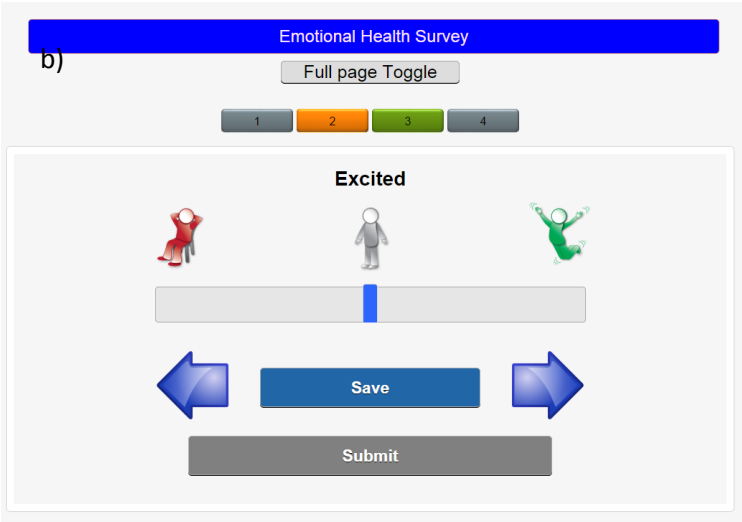


Figure 2: Survey tools for Hft. a) shows an online survey for a user to record their experience of their emotional health, seen from the Administrator view. b) shows the "accessibility" view, showing just one question at a time.

Data is visualised on the website interface for every user (see Figure 3), forming a searchable "case history". It is also possible to record and display events in a user's life, and interventions performed by support workers (see 2.1.4), and these appear on the data view.

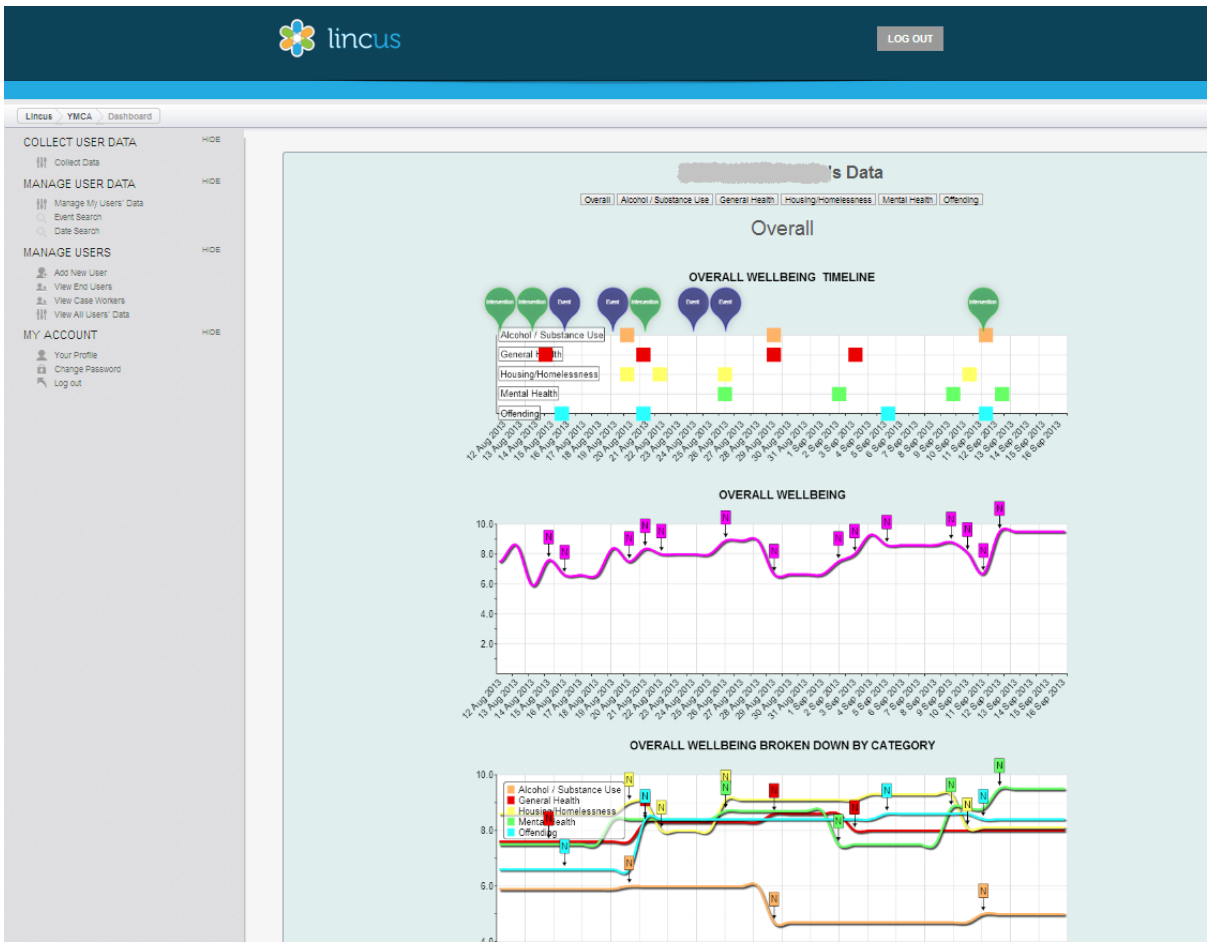


Figure 3: Viewing a user's data on the Lincus dashboard: Analysis view

There are a number of other data visualisations available within Lincus on request. Figure 4 shows an "Advanced Package" view which can be included.

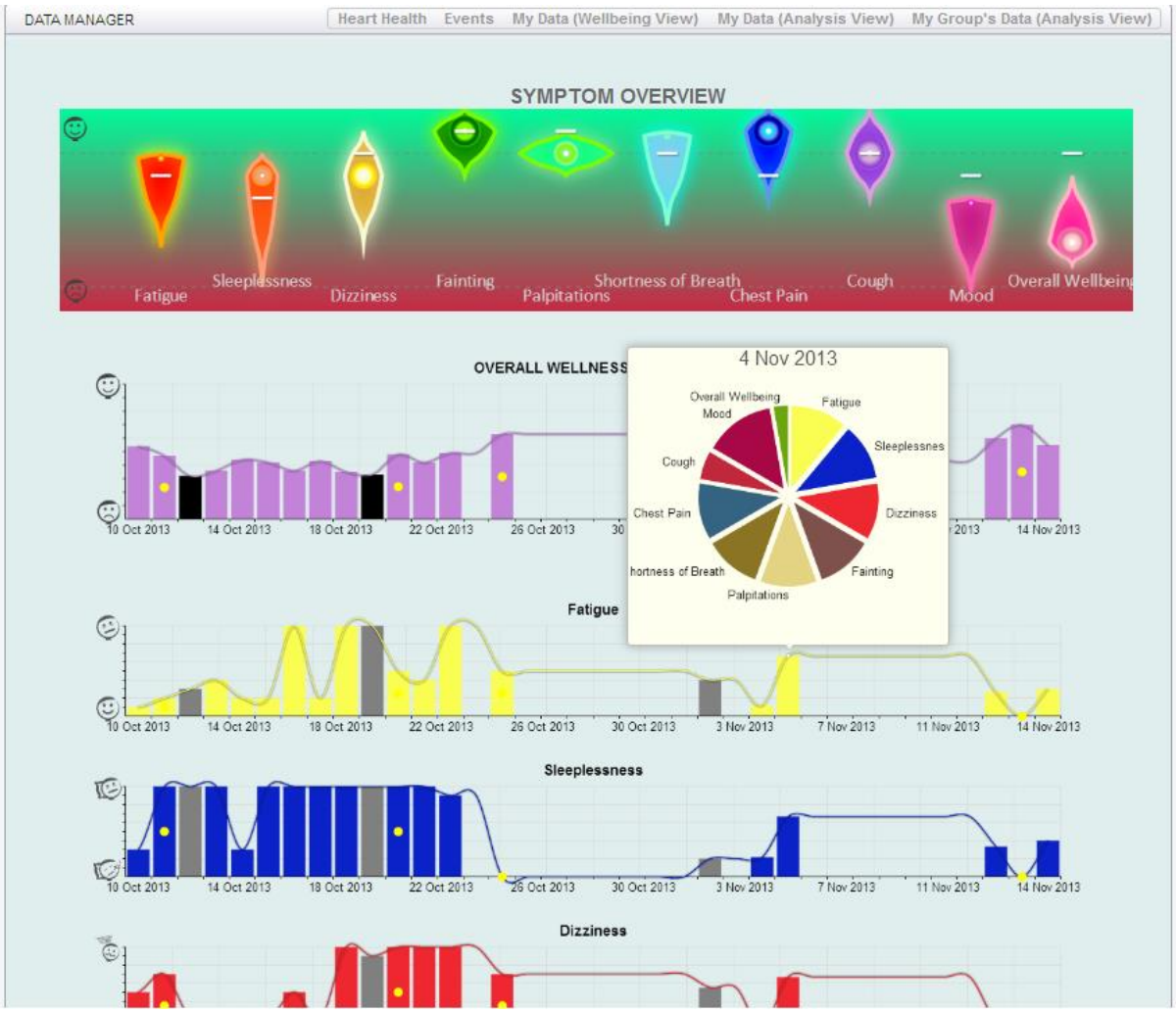


Figure 4: Viewing a user's data on the Lincus dashboard: Wellbeing View

2.1.5 Combining User 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. It is possible to perform basic data analysis, such as OLS fit lines (with appropriate uncertainty measures). For example, Figure 5 shows how perceived user wellbeing changed throughout the course of the YMCA trial study (an 80% improvement overall - in fact, over the course of the Lincus trial a measurably positive effect on the population involved was observed in almost all areas measured.)

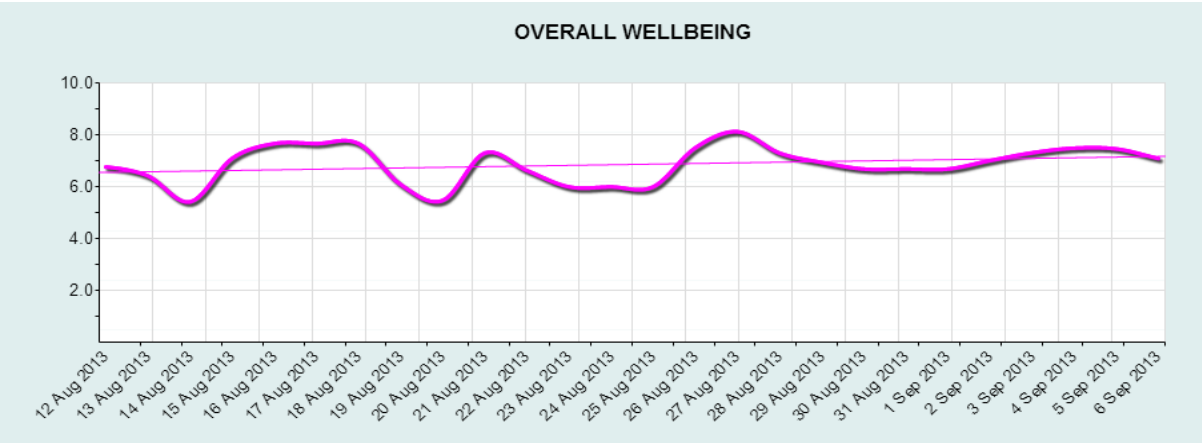


Figure 5: Average wellbeing scores of all participants throughout the YMCA trial study. The data is fitted with a smooth spline for ease of reading (thick line). An ordinary least squares line is fitted (thin line) to demonstrate the overall trend.

2.1.4 Events and Interventions

Lincus users are able to record life events, and interactions with various services, as they occur. This data enables the user to see the general effect certain events have on different areas of their wellbeing. It also allows organisations to view average effects of events on their populations.

There are two types of recordable occurrences, referred to as “Events” and “Interventions”. Events are things that happen to a person – they are taken to hospital, suffer a bereavement, they are arrested, or receive an unexpected cheering visit from a relative. Interventions on the other hand are performed in a pre-planned way with the user’s wellbeing in mind. Interventions might be being given a new type of medication, being placed on a drugs and alcohol program, being given assistance in finding accommodation, or getting help doing their shopping. Interventions are commonly performed by the staff of organisations who are supporting the relevant user groups, or their associates.

Measuring the effects of their interventions on the perceived wellbeing of user groups as a whole provides organisations with a measure of how valuable the interventions are, whether they produce a measurably positive (or negative) effect, and also over what sort of timescales their effects are felt.

Figure 6 shows the result of a search for the effect of a YMCA-provided “External Activity” on the mental health profile of participants in the program. The majority of these involve a visit from an external professional body, resulting in inclusion in a detox program or similar. This shows that average mental health scores drop by around 70% immediately following such interventions, suggesting that these interventions immediately cause users to feel more negative about their wellbeing, but they recover back to previous levels around 4 days later. More data would be needed to see whether the longer term effects are positive – do the users who receive this intervention feel better a few months or a year later than those who do not?

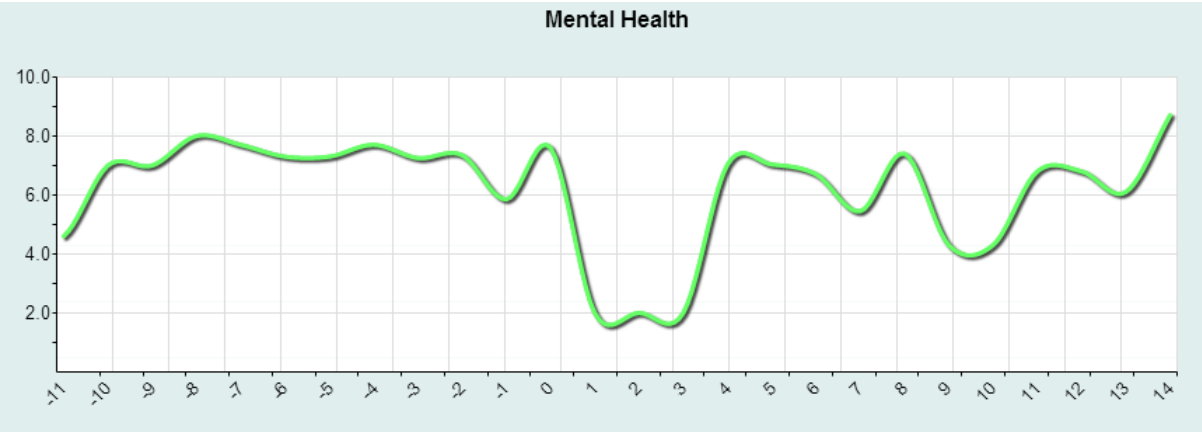


Figure 6: YMCA: Averaged Mental Health scores in the fortnight leading up to, and following, an External Activity intervention. The date of the event is marked 0 on the x axis, 1 indicates the day after the event, -1 the day before, etc.

Similarly Figure 7 shows the result of a search on "Severe Intoxication Events", when YMCA staff reported that a user was seriously intoxicated (causing a problem). This time, a drop in user-reported satisfaction with their housing situation of around 70% is clearly visible the day before the intoxication occurred, possibly indicating a causal link between housing dissatisfaction and excessive alcohol consumption.

Figure 7: YMCA: 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 is the day after the event, -1 the day before, etc.

There were too few participants in the YMCA trial to reach meaningful conclusions in these cases, but this does provide a hint of the power of using this system to combine data from larger groups of individuals.

2.1.6 Viewing Organisational Data

Lincus allows organisations to effectively track their own workload and costs, as well as measure how effective various interventions are in improving perceived wellbeing over different timescales. Some additional reporting tools are available so that centre managers and administrators can see which staff are performing interventions, with what frequency, in order to track work flow. It enables the manager to make decisions on allocation of funds and resources. Figure 8 is an example of an organisational view of interventions data performed during the YMCA trial.

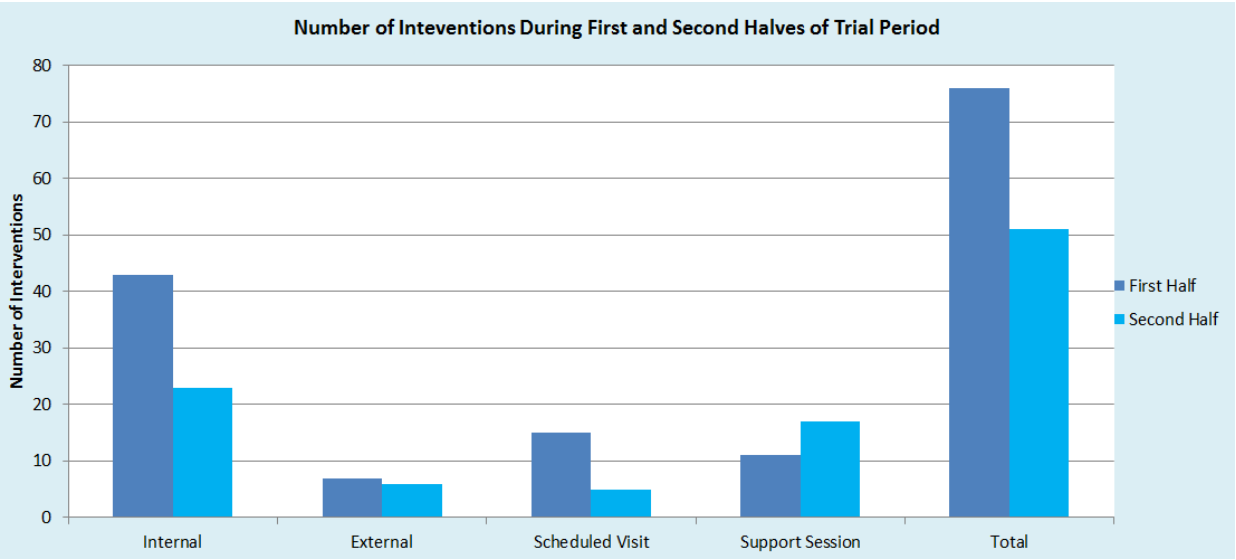


Figure 8: Overall number of interventions of each type performed by case workers over the first and second halves of the YMCA trial.

2.2 Symptom-Tracker App

In 2010 Rescon developed the Symptom-Tracker app, which enabled athletes to quickly and simply enter details of their daily nutrition, activity, and fill in a survey of symptoms related to over-training. This surveying tool was a precursor to Lincus. The nutrition and activity components were built into Lincus for One Precious Life (see section 3.2.3).

2.3 Visualisation and Analytics Dashboard

In parallel to Lincus, Rescon has developed a Visualisation and Analytics Dashboard. This was initially developed for Rescon's work with ECG heart traces, and is now also being used by groups within Duke University to analyse genetic datasets as part of the DARPA Biochronicity program. Work on this system has influenced the new, more interactive data analytics and visualisations built into Lincus for OPL.

2.4 Article Publishing Protocol

A Wordpress news site has been used for reporting Rescon-related news. This is accessed by a purpose-built XML service which pushes the article data to other sites which then format them to appear seamlessly built in to the front end site. This allows us to publish well-formatted and searchable articles to non-wordpress pages, with an RSS feed available. This now forms the basis of the OPL Information Hub.

3 ONE PRECIOUS LIFE TECHNOLOGY

As part of the One Precious Life (OPL) project Lincus has been significantly expanded, and made more accessible. Aspects of the Visualisation Dashboard have been incorporated. Lincus can now be accessed directly from a public-facing website, which also includes access to informative and motivational articles on health and wellbeing.

The public One Precious Life website also provides access to a large number of informative articles on health and wellbeing, and connects users to the One Precious Life E-books.

Additionally, a wrist tracker was released to OPL participants, with an app built by Rescon. The app reads and writes data to the wrist tracker, and enables the user to upload their pedometer data from the tracker to their Lincus account.

3.1 Communication and Education

A public-facing website www.opl.rescontechnologies.com was developed to serve information to the public, and provide an access point for Lincus. It was designed to be friendly-looking, easy to use and understand, Figure 9 shows a screenshot of the front page. Users and Coaches can register to use the Lincus system here, and log in.

Figure 9: The front page of the One Precious Life website

Articles are written by members of the Rescon team and associates, in the categories of "Technology", "Mind", "Body" and "Nature's Pharmacy®". These are searchable health and wellbeing blogs designed to provoke thought. Example titles include: "Green Fingered Therapy For Dementia", "Could Some Cases of Alzheimer's Disease Be Preventable?", "LEO - Thigh Worn Wearable Tech For Sports" and "Stress, The New Risk Factor For Strokes". Figure 10 shows a snapshot of the Info Hub main page on a particular day.

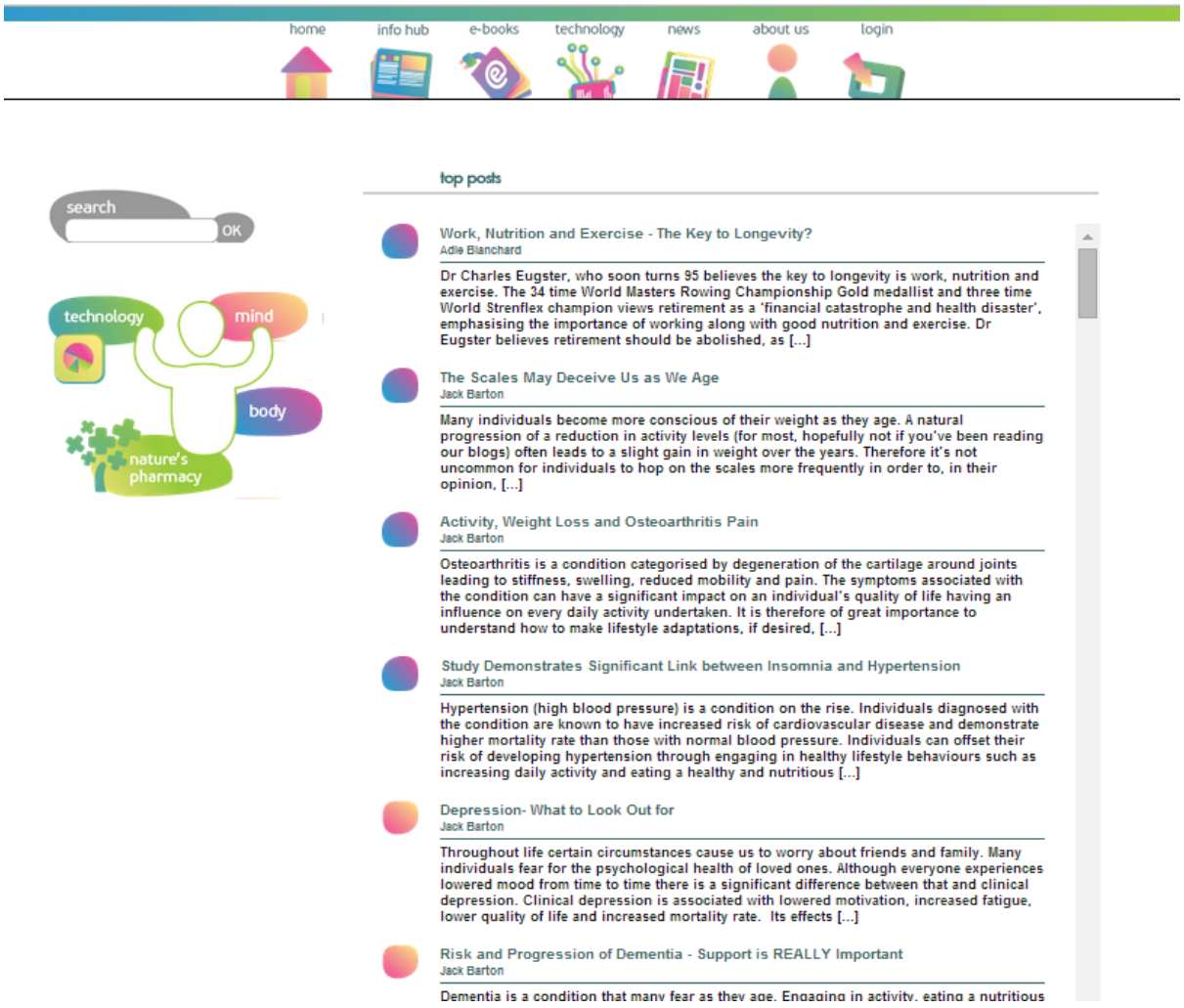


Figure 10: The Info-Hub main page

The first of a series of Ebooks, "The Family Guide to Long Term Conditions" was also developed and released onto Amazon Marketplace where it can be downloaded on kindle. A second book "Things we never talk about", accompanied by a series of humorous and engaging animated videos, is in production at present. This aims to cover topics such as bodily functions and intimate itching that are not usually discussed. Ebooks are showcased in the one precious life website (see Figure 11) and are searchable by keyword alongside the blogs, so users can access information from multiple sources.

Figure 11: The Family Guide to Long Term Conditions, displayed for sale in the one precious life website

3.2 Lincus for One Precious Life

A large number of changes to design and structure were implemented in order to make Lincus more suitable and appealing for the general public.

3.2.1 Enhanced User Control

Previously the bulk of the Linux software was available to support workers and managers, who were able to register users and collect their data for them. Lincus was redesigned to be more directly usable by the end user, and to allow them to self-register and sign up for services.

3.2.2 Coaching

Lincus users are provided with access to a choice of coaches. They are able to select an appropriate coach or coaches to suit their needs and request the coach to work with them (see Figure 12). The coach is able to help the user set goals and offer advice and support. The system has been built to enable the setting up of alerts so that a coach is notified if sets of symptoms for particular users are seen to deteriorate (currently in development). The coach has a monitoring dashboard where alerts are shown and user requests can be accepted or rejected (Figure 13). Coaches are also able to add and monitor their own data.

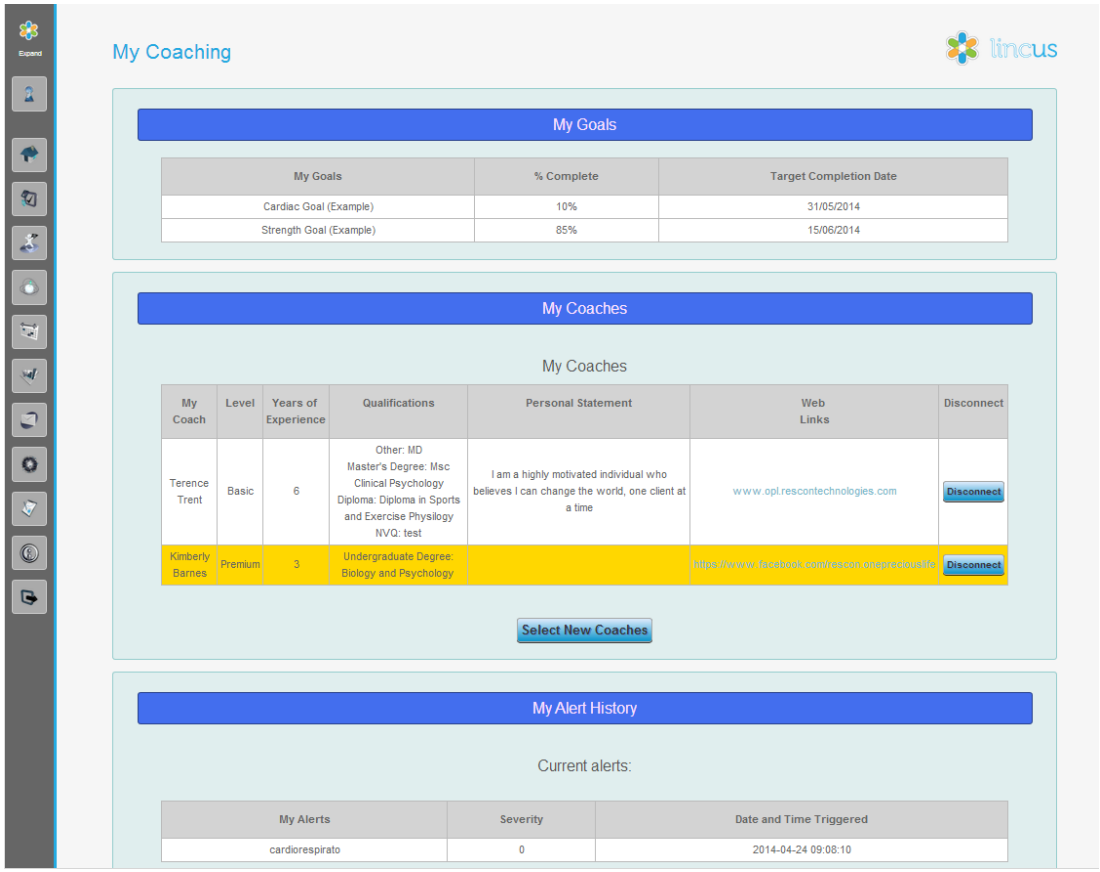


Figure 12: Online access to coaching

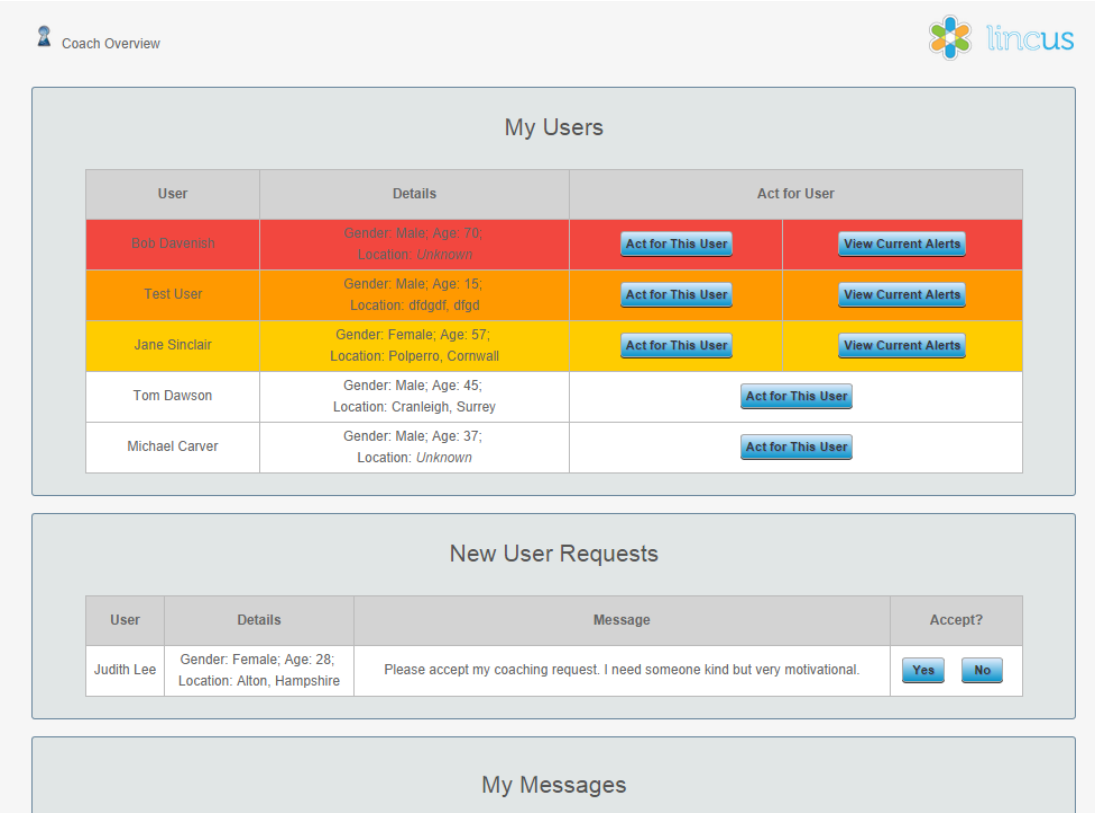


Figure 13: Coaches dashboard

3.2.3 Customised Interfacing and Choice

Lincus was redesigned to be more user-friendly and appealing. A number of skins were developed, enabling the end user to choose a look and feel for the system that appealed to them. Some examples are shown in Figures 14 and 15. The user is also able to select their own sets of surveys related to their needs, see Figure 16.

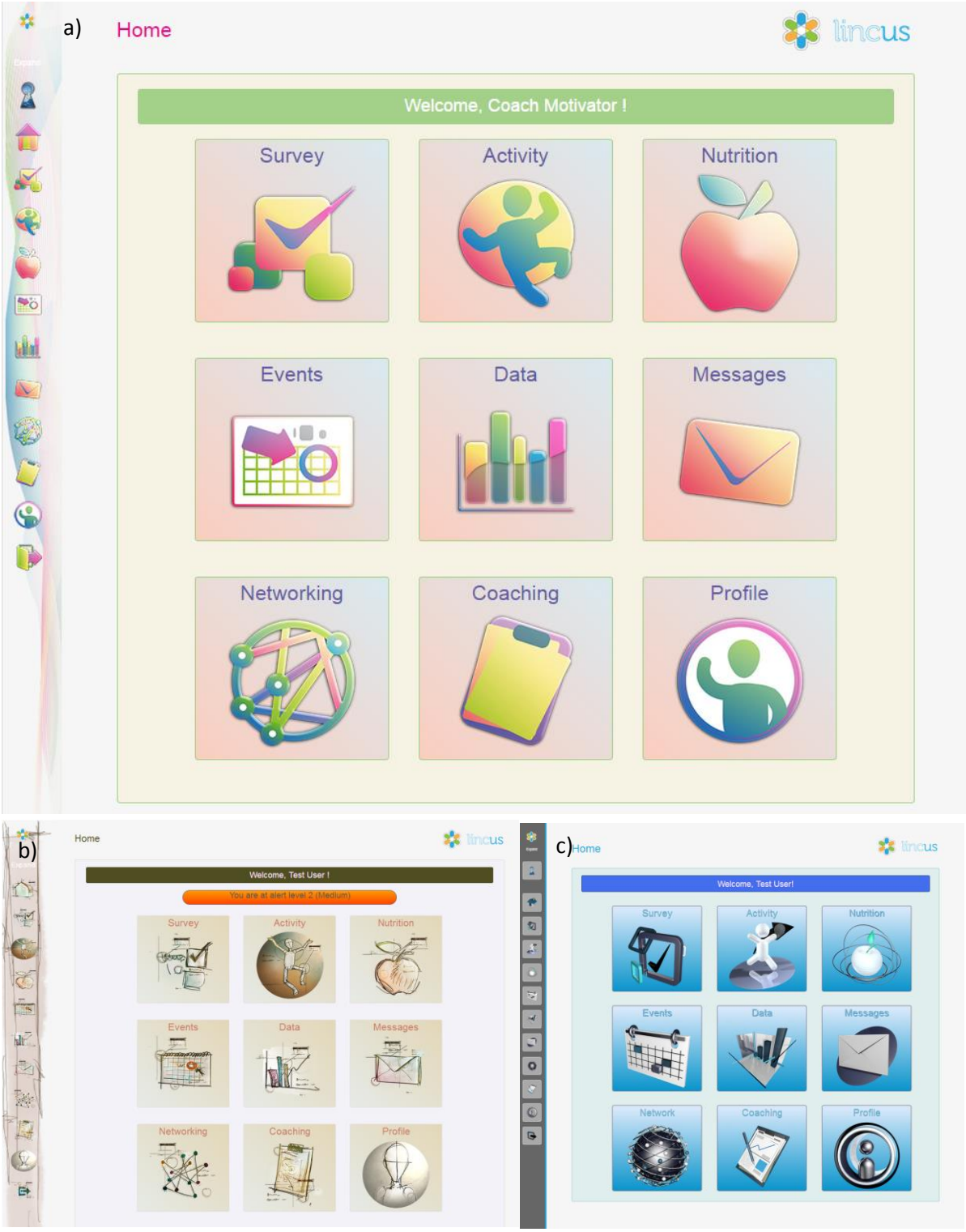


Figure 14: Examples of home interface variations for Lincus: a) Friendly b) Da Vinci c) 3D

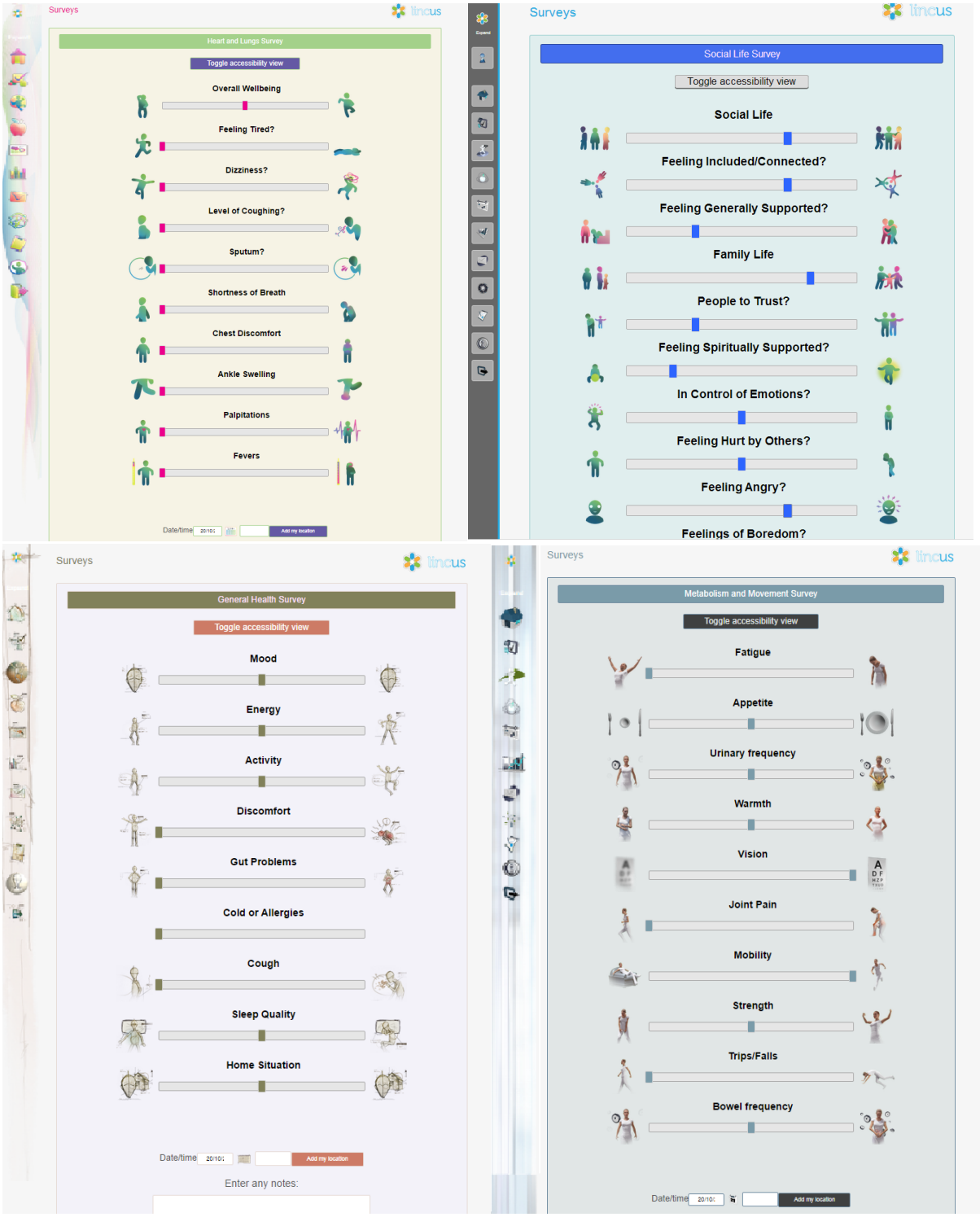


Figure 15: Examples of surveys for Lincus: a) Friendly b) 3D Friendly b) Da Vinci c) 3D Female

Figure 16: Different survey options (a) Friendly interface b) 3D Male interface).

As well as selecting surveys, the user can also optionally track their nutrition, activity and weight. Nutrition and activity modules had already been developed in the original Symptom-Tracker app, but had not previously been used in Lincus. The activity and nutrition modules are based on a "three click" concept – the user selects for instance a type of meal (such as lunch, an alcoholic beverage or a snack), and then simply estimates on a sliding scale how large the portion size was (from small to large) and how healthy (from unhealthy to healthy). Algorithms on the back end estimate a rough calorie count from the user's BMI and usual activity levels (and in future will "learn" from a user over time what they consider a large meal!) and convert the food into a point score for comparison with weight and other data. The activity module works on a similar line, in which the user selects their type of activity, how long they did it for, and how intensely. See Figure 17.

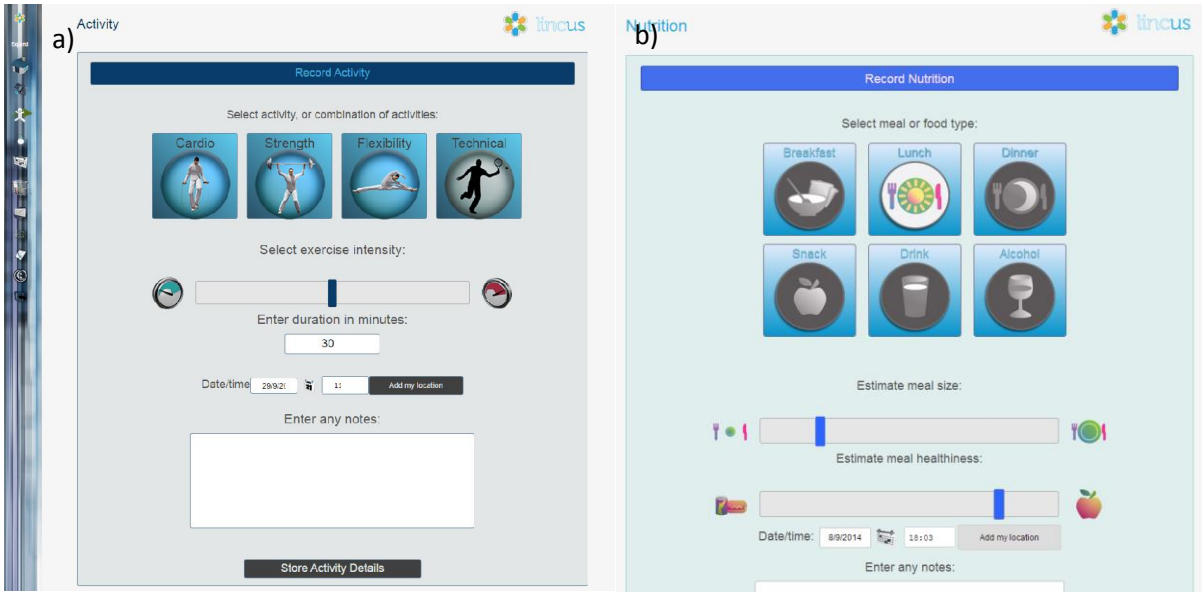


Figure 17: a) Activity module (3D Male interface) b) Nutrition Module (Friendly interface).

3.2.4 Accessibility

The accessibility view which was developed for Hft was included in this version of Lincus, with appropriate icons, and in large font (Figure 18). For users who did not wish to use the Lincus interface at all, surveys could be printed off by the coaches (similar to Figure 15), circled in pen by

the user and returned to the coaches, who would be able to enter the data later on behalf of the user.

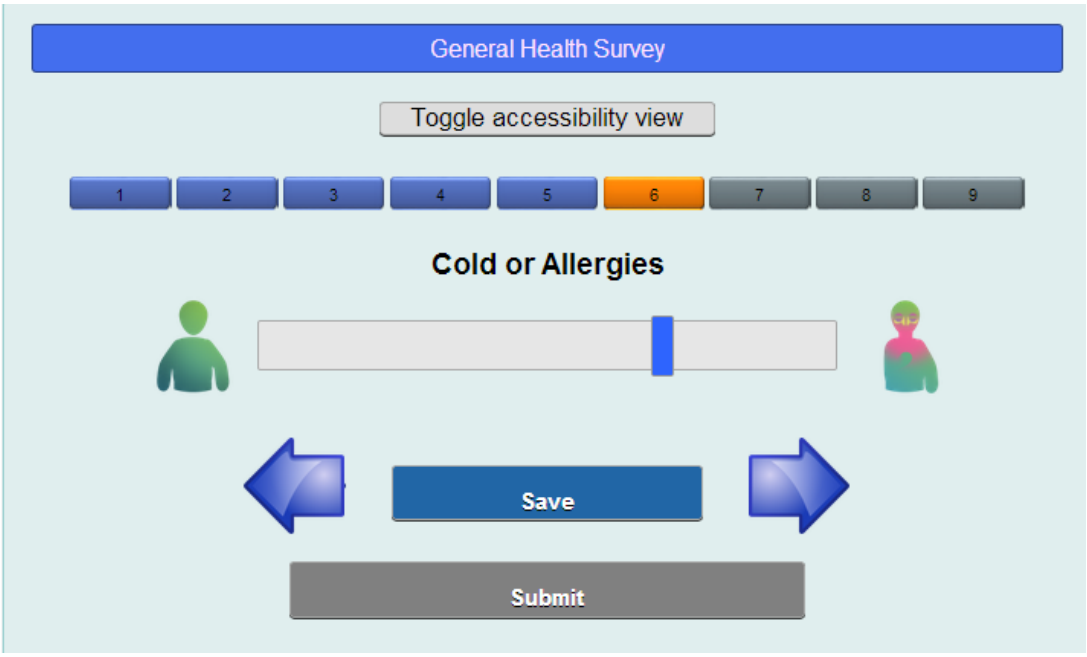


Figure 18: Survey accessibility mode

3.2.5 Networking

The user is able to make connections with other users of the program in order to support one another. The can build a network (Figure 19) and send messages to each other (Figure 20).

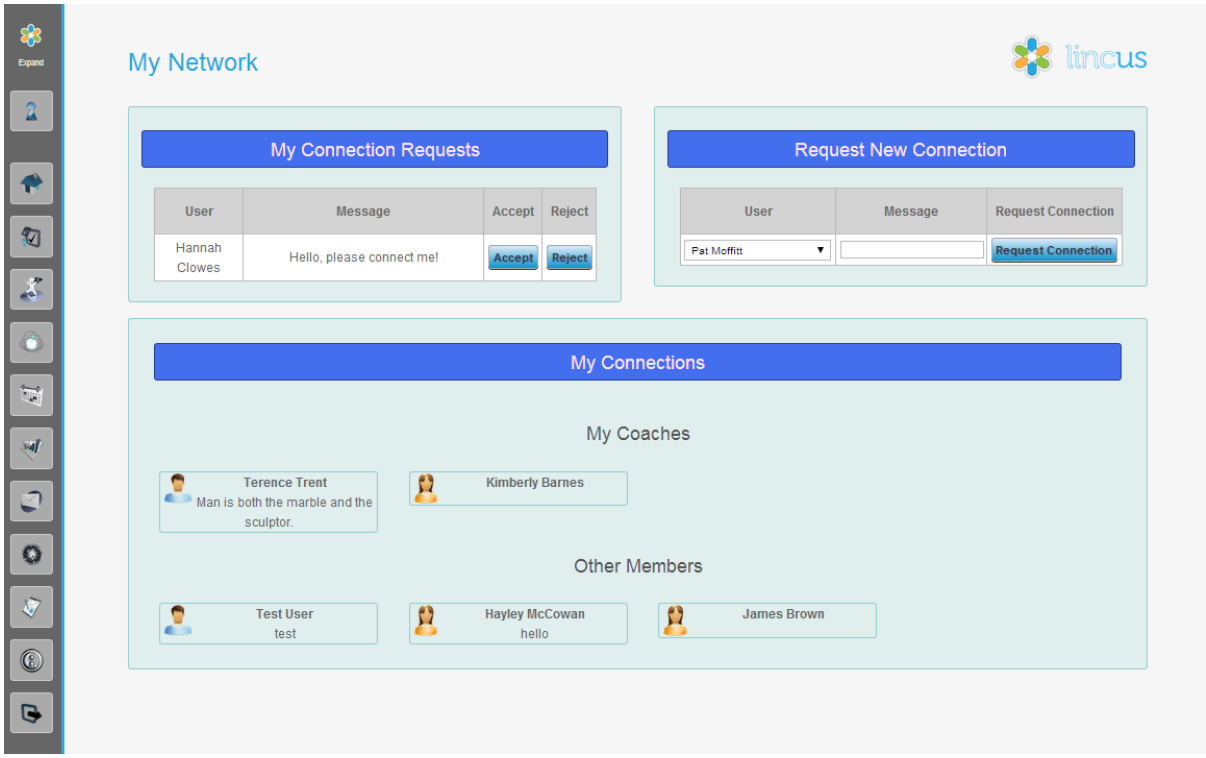


Figure 19: User networking

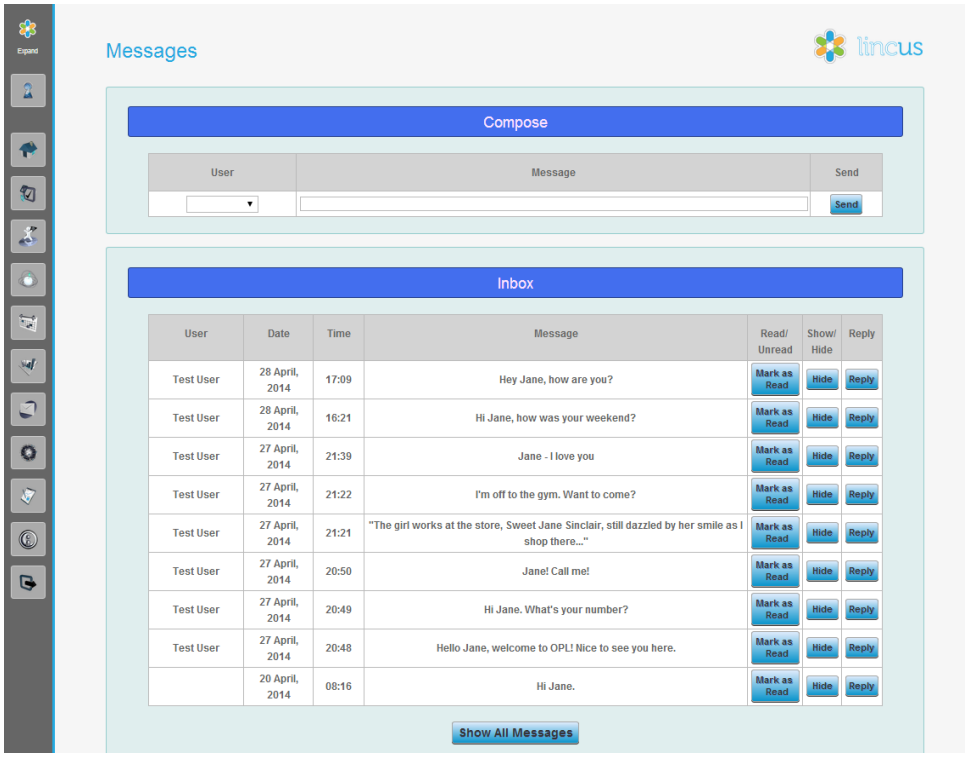


Figure 20: User messaging system

3.2.6 Data View

Users are able to view their data and search over time. There is a simple graph view (Figure 21) and a more complex analytic view (Figure 22), where different forms of data can be included. More views are being designed.

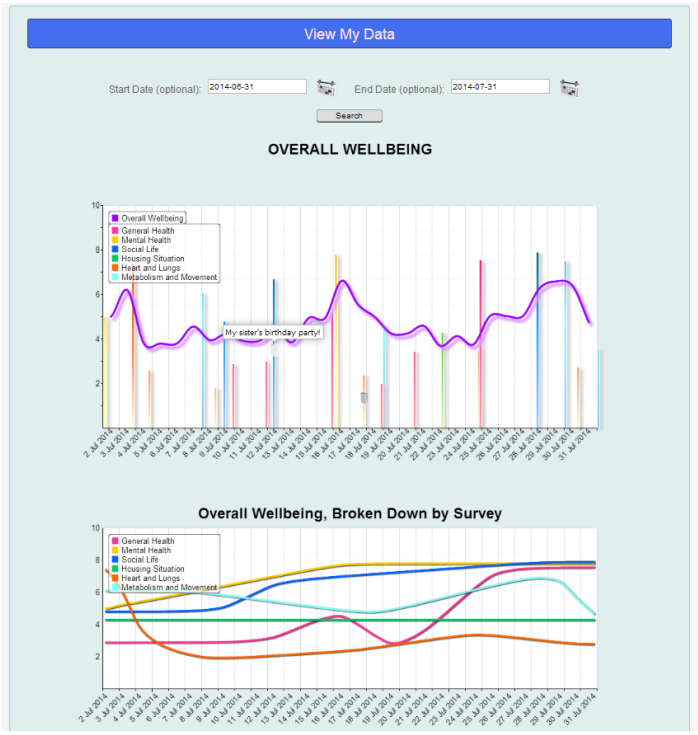


Figure 21: Basic data view

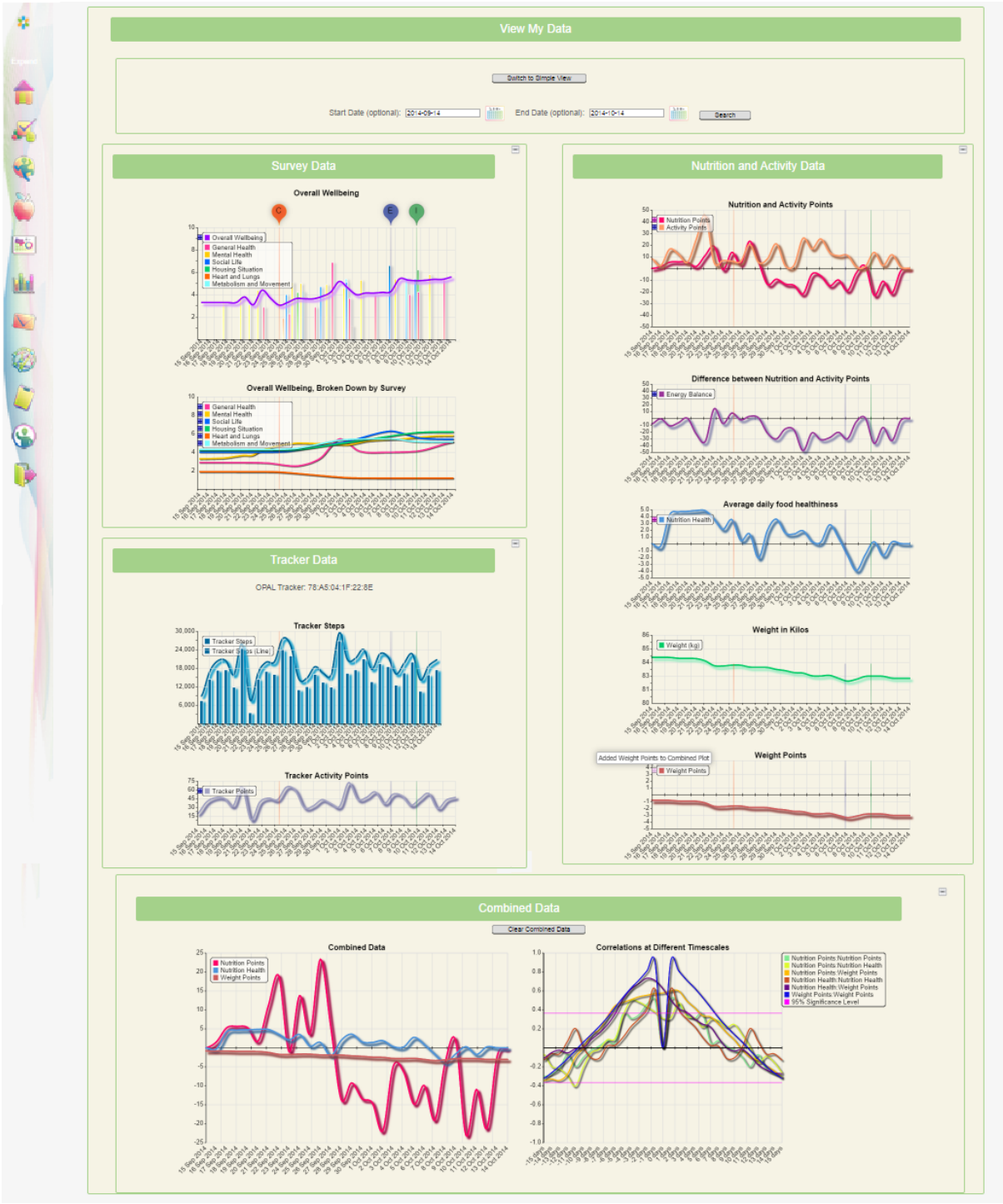


Figure 22: Analytic data view

It is also possible to view combined data for groups of users, see Section 4.

3.3 OPAL-Tracker

All program members were given a wrist tracker, which acted as a pedometer, in order to enable them to track how active they were through the program. They agreed, with their coaches, on daily steps targets that they aimed to achieve. The trackers were provided by Rescon, and a brand, OPAL, has been created separately to the OPL project (See Figure 23). There is a separate website, www.opal-tracker.com with more information.

a) b)

Figure 23: a) OPAL tracker logo b) Graphic of OPAL wrist tracker

An Android app was developed, and given to the OPL coaches to use (Figure 24). The app transmits relevant personal data to the tracker (via low-energy Bluetooth). It downloads all data from the tracker, and uploads pedometer data to the Lincus site, where each tracker is connected to a specific user account.

Figure 24: Screenshot of OPAL-tracker app showing how many steps a participant has taken today, their distribution through the day, and how close to the day's steps target the user currently is.

4 PARTICIPANT DATA OVERVIEW

The One Precious Life project trail included only 8 active users. This makes it impossible to draw meaningful conclusions about the effects of using the technology, or of providing human coaches to the end users. The average wellbeing scores of users went up over the course of the study, by about 10% (Figure 25), but the calculated uncertainty on this value is nearly 20% (meaning that the "real" wellbeing scores were likely to have changed by somewhere between -10% and +30%). A much larger population would be required to form any conclusions.

Figure 25: Screenshot of OPAL-tracker

Figure 26 shows the number of users uploading activity tracker data on different days of the trial (they joined and left the trial at different dates). Users hit or exceeded their target steps on 54% of days. One user did not manage to upload any data.

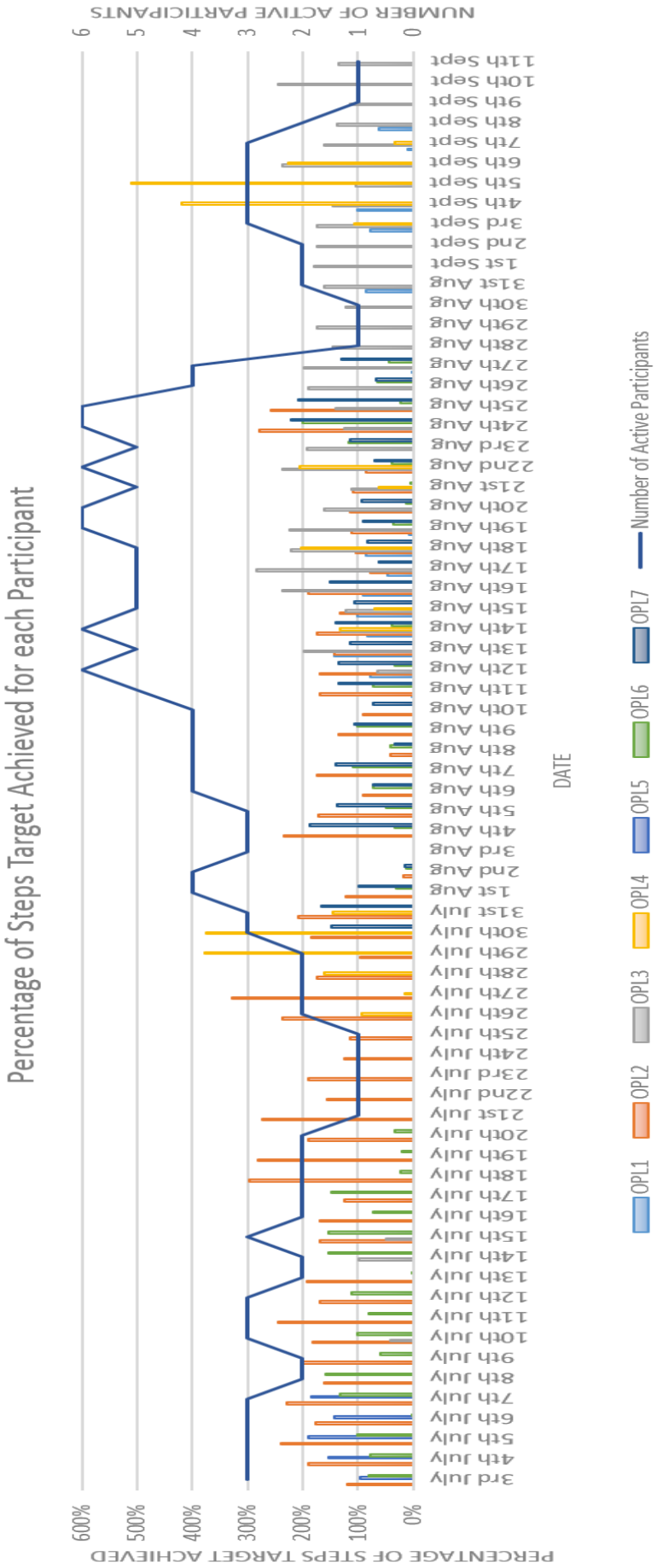


Figure 26: Tracker pedometer data uploaded by users throughout the trial.

5 FUTURE DEVELOPMENTS

The following improvements (amongst others) are currently on the timeline for development in the near future.

5.1 Organisations and Medical Professionals

Re-work the organisational levels to fit in with new structure. Allow users to associate with organisations (with the organisation's agreement) and allow organisations to create member users.

Separate dashboards for medical staff. Connect Lincus to N3 system to allow medical workers to allow patient records to be viewed and interventions connected to Lincus.

5.2 Further Modularisation

Greater choice of optional modules (e.g. sleep quality, intimacy, range of long-term-condition surveys). Organisations able to select modules for their associated users. Different levels of users have different choices available

5.3 Increased Availability of Quantitative Measurement Devices

Building in inputs from other measurement devices such as those from Rescon, Fitbit, Jawbone, Wireless scales and other 3rd party devices. Users are able to register their own devices on the system and automatically update their measurements when they use the devices.

5.4 Broader range of Data Visualisations

Broadening the range of data views to suit all tastes, from simple colour coding with icons which are very easy to understand to highly technical views with built in options for bespoke data analysis.

Comparisons will also be available with selected user groups, so that the users can compare their data with the average for their demographic (or other demographics that they select).

5.5 Development of Alert Algorithms

Work is ongoing on design and testing of algorithms to alert selected users if people show deterioration in their condition. For example, a person with a history of depression might trigger an alert if their mood scores deteriorate significantly, or someone recovering from surgery who is increasingly reporting feelings of unwellness might trigger an alert. The alert will be sent to individuals authorised by the user, such as their family members, closest friends and healthcare providers. Alerts can be sent within Lincus or by email or SMS, and the system may record whether someone appropriate has responded, or whether to escalate the alert.

6 CONCLUSIONS

The InnovateUK-funded One Precious Life project for Long Term Conditions as part of the Long Term Care Revolution provided both the funding and a catalyst for Rescon to both develop internal and create new technologies. Rescon now has a much greater capacity to support the individuals who are motivated to be better through accessible education, self-tracking and other eCoaching tools. Rescon is now strategising internally on the best way to commercialise these tools and is actively seeking partners to allow the tools to be available and promoted at scale.