Setting up a High Intensity User service

An NHS RightCare resource pack
Setting up a High Intensity User Service
A Resource Pack

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Foreword

Foreword from Rhian Monteith, Programme Lead who developed the NHS Rightcare High Intensity User approach, giving her own personal reflections on the service.

“Hi, You…”

As you look over RightCare programmes you’ll read a lot about High Intensity Users (HIUs). It’s the current accepted phrase but, while an improvement on “Frequent Fliers” or other lazy pejoratives, it doesn’t evoke the feeling that a person is at the very heart of it.

Our work with HIUs has shown, time and again, that when you put these people in a box and label them - regardless of the label - you miss the point about how best to help them.

Our experience shows that the underlying personal reasons for HIU behaviours do not lend themselves to models, averages, or trend-lines. They cannot be generalised. They cannot be viewed usefully from the safety of an office, nor do they allow the luxury of a top down view. And this is why solutions designed at a safe distance for an abstract ‘typical’ HIU tend to fail.

We have succeeded by starting and finishing our interventions with the individual. We test what might work in the field; we’re fearless about the risk of mistakes; and we’re rigorous in learning from those mistakes before we move ahead.

Of course we want to lead these people away from their behaviour, for their own benefit and for the benefit of a stretched public service. But in order to Lead, we must first Serve.

We serve by listening before we decide. By understanding before we act. By personalising before we deploy.

“Serve to Lead.” It’s the motto of the Royal Military Academy, Sandhurst, and it’s right at the heart of this project.

When we meet a High Intensity User, we have a choice: to label them ‘HIU’ and trust them to the care of a standardised playbook; or to look the individual in the eye and say “Hi, You…”

And then listen, learn, and act.

Rhian Monteith, High Intensity User Programme, NHS RightCare

Winner of the Kate Granger Award for Compassionate Care 2018.

#hello my name is…
1. About this resource pack

Resource packs are intended to support local health systems who think that these innovations can be adapted and adopted to support an improvement opportunity in their local area. They are not intended as guidance and it is up to the local community to ensure that the innovation is:

- Suitable for the local population
- Supported by appropriate governance
- Evaluated to ensure that the innovation is having an impact

The resources provided as part of the packs are an example of those used in a particular place and can be adapted, built on and improved to suit local circumstances.

2. Introduction

Quick facts

- Annual costs of one WTE (Whole Time Equivalent) resource.
- Time to set up service – three months.
- Expected timeframe for return on investment – three to six months.

The High Intensity User (HIU) service (first launched in Blackpool) offers a robust way of reducing frequent user activity primarily to A&E and non-elective admissions but can also contribute to reducing other avoidable unscheduled care contacts.

Now live in over 80 CCGs across the country, the programme is freeing up front line resources to focus on other patients and reduce costs. It uses a health coaching approach, targeting high users of services and supports the most vulnerable individuals within the community to flourish, whilst making the best use of available resources.
Analysis of existing sites show that on introduction of the service, at an average annual cost of £50,000, a positive impact is achieved within the first three months. For the individuals targeted, when the three months’ post intervention activity was compared with the three months’ pre-intervention activity:

- 999 calls were down by 15%
- A&E attendances were down by 38%
- Admissions were down by 51%
- Individuals flourish with many reconnecting with their community, developing from negative to positive contributors to society, delivering significant economic benefits.

Whilst the intensity of service use for some individuals may not have continued at quite the same scale had there been no intervention, the cohort is replaced every three to six months by others at the peak of their service use. Therefore, the benefits available to the population and health economy keep repeating. There will always be a top 50 HIU users (albeit reducing in frequency as the programme progresses and improves its pro-activeness), so it’s a non-recurrent saving that can be delivered every year with a new/different cohort.

Established services have demonstrated that post intervention, activity remains significantly and sustainably reduced for the duration of the service.

There are many individuals who have been stuck in the ‘revolving door’ of unscheduled care for years who clearly benefit from a different approach, like the one described in this resource pack. Therefore, this pack has been put together to share the 80+ live CCG’s experience and offer support to other areas who are thinking about doing something similar. As mentioned above, it is not intended as guidance.

Thank you to the CCGs for sharing their resources and learning.

“This scheme has saved my life – I don’t recognise the person I was then.”
Service user

“This scheme helped to shape a service around clients’ needs rather than making clients fit in to the rigidity of health/social care services – it’s person centred”
Service provider
About NHS RightCare

NHS RightCare delivery is a model of: Diagnose, Develop, Deliver.

NHS RightCare teams work locally with systems to present a diagnosis of data and evidence across that population. NHS RightCare Delivery Partners and their teams work collaboratively with systems to look at the evidence to identify opportunities and priorities. Using nationally collected robust data, this collaborative working arrangement helps systems to make improvements in both spend and patient outcomes. Together they complete delivery plans on a continuous basis, to evaluate the system and establish a baseline to identify and maximise opportunities and turnaround issues. Throughout this process they ensure patient care is at the top of agenda by promoting the strong clinical interventions developed with the Senior Clinical Advisors and key stakeholders.

3. Is a similar service right for your health system?

The High Intensity User service contributes to the delivery of the NHS Long Term Plan by reducing demand in Urgent and Emergency Care.

As part of the 2019/20 NHS Operational Planning and Contracting Guidance, all health systems in England must implement a High Intensity User service.

NHS RightCare Delivery Partners and their teams support local systems to use this resource pack to implement the HIU model. They can also work with you to identify the potential opportunity for your system. Alternatively, systems can approach the Business Intelligence team at the targeted Acute Trust or the CSU to complete the following starting point data form to clearly identify the need for the service and the size of the challenge.
The High Intensity Users programme is an example of innovative service delivery where NHS RightCare has supported the transition from innovation to mainstream service delivery. As HIU services are spread across the country it is important that implementation and delivery is evaluated in terms of impact. There is an expectation that all local health systems should develop an approach to evaluation that will allow the learning to be used to identify what works well for the benefit of patients.

Harnessing this local practice, the national RightCare HIU team will continue to translate and disseminate knowledge and good practice through the HIU resource pack.

4. About the National High Intensity User Service

The service comprises a High Intensity User lead that proactively makes telephone contact with the most frequent attenders of the local A&E to find out how the local health economy could better meet their needs.

The objectives of the service are to:

Measurable:
- Identify those at greatest risk of A&E attendance and non-elective admissions.
- Proactively manage a rolling cohort of High Intensity Users using a truly personalised approach.
- Coordinate, sign post and oversee other identified High Intensity Users.
- Reduce 999 calls as a natural by-product.
- Reduce A&E attendances and avoidable NEL admissions.

More difficult to measure but essential:
- Form robust network of community health, social care, mental health and police to manage patients, creating true integrated working.
- Provide a service driven by quality with positive human outcomes observed.
- Act as a conduit to negotiate and de-escalate issues before a crisis occurs; a situation which has historically led to a destabilisation of their condition and resulting in a 999 call / A&E attendance.
- Improve communication and partnership working between those involved in patient care 24/7.
- Assist other providers to identify patterns and ‘causal factors’ which trigger relapse behaviours in former High Intensity Users in order to shape future commissioning of service and/or demand/capacity planning.
Empower patients to self-manage to enable discharge and to switch them from negative to positive contributors of society.

• Drive equality and patient voice.

The principles of the service are to:

1. **Identify.** The top 50 High Intensity Users are identified utilising A&E data systems. Some additional clients are selected due to their vulnerability as opposed to chronically high use of health services. This group may be refereed into the service by concerned organisations as having called 999 or presented to A&E fewer times in comparison to others, but presented with high risk episodes of self-harm or homelessness.

2. **Personalise.** The individuals are contacted directly by a phone call from the HIU lead. The calls focus on the individuals’ issues, identifying, de-medicalising, de-criminalising and humanising their needs to uncover the ‘real’ reason for calling 999, A&E or an admission.

3. **De-escalate.** Many individuals use health care frequently due to an escalation in their social, emotional, financial or family issues; an unmet need. Competent de-escalation is facilitated by offering immediate access to an appropriate coaching support service (the HIU lead).

4. **Discharge.** Discharge from the project to community support services takes place when the individual requires on-going support but not at the intensity or specialism of the HIU lead. Many individuals, following initial support from the High Intensity User service are discharged without the need for follow up but this needs to be done skilfully and mindfully. Many are reconnected to their community with friends and purpose. The word ‘discharge’ is not used as people hear ‘rejection’ so connecting individuals to the community without immediate relapse requires consideration.

5. **Manage relapse.** Once supported by the service, individuals often begin to feel more positive, decrease their dependency and improve their personal outcomes. Relapse can occur when individuals begin to feel isolated again or feel they can no longer cope with a change in situation. They may begin attending A&E again but more usually, these people instead contact the HIU lead directly who immediately picks up their issue and helps them navigate through the difficult time rather than returning to their ‘old’ behaviour of attending A&E.

6. **Quality of intervention.** Higher quality more personalised and effective interventions will create robust connections and positive outcomes for individuals and deliver financial savings to the system with increased pace.
A personal account of the National HIU programme lead’s approach is included in the Appendix of this document.

5. Key success factors

Based on national feedback, there are five key success factors that are viewed as critical to the delivery of the desired outcomes:

1. **Select the right person for the role** – you need someone with high emotional intelligence, resilience and a natural ability to problem solve creatively.

2. Provide your High Intensity User lead with training, **ongoing support and coaching** to prevent burn out and to sustain successful outcomes over time. It also allows the programme to run efficiently with reduced effort required by the CCG at the beginning.

3. **Give them freedom to act and freedom to innovate** – concentrate on the outcomes you want rather than being prescriptive about how they will be achieved. Be brave - the right person will guide the way.

4. **Commit for a minimum 18 months** – you will need this time to attract the right candidate to implement the approach and to sustain later cohorts.

5. **Source an automated, independent evaluation method** that allows you to demonstrate quantitative and qualitative outcomes so you can evidence success.

6. Implementation Timescales

It is tempting to wait until all parts of the plan is in place to begin the programme but this is not necessary and often, by the time the all the relevant information is gathered and services involved are briefed, the information is out of date or leads to further questions. The advice from NHS RightCare and the national lead for the programme is to ‘Be Brave. Just start’ and adapt as you go along.

From appointment of the worker, **timescales for implementation** can be relatively quick if all stakeholders are on board. The month prior to implementation requires identification of the cohort and getting data sharing agreements in place so that the programme can hit the ground running from the outset.

Indicative timescales could comprise:

- Month 0 – Appointment of worker, preparation & training.
- Month 1 – Relationship building and start work with first cohort.
- Month 3 – Should start to see some real results in first cohort who should be ready for discharge and a new cohort starts.
7. Commissioning and establishing the service

There is no one, ideal way to set up an HIU service – each site differs to suit local circumstances. However, based on the experience of sites to date, the table below includes some of the infrastructure and processes you may want to consider for a successful implementation, along with some Frequently Asked Questions.

<table>
<thead>
<tr>
<th>Infrastructure and processes to consider</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Making the case for change/commissioning the service</strong></td>
</tr>
<tr>
<td><strong>Starting point data</strong></td>
</tr>
<tr>
<td>Complete the starting point data to identify the need for the service.</td>
</tr>
<tr>
<td>Starting Point Data Form</td>
</tr>
<tr>
<td><strong>Business case</strong></td>
</tr>
<tr>
<td>If the data identifies an opportunity to implement the HIU programme, a business case will be needed to gain approval for the service.</td>
</tr>
<tr>
<td>See the following sample documents to adapt and add in your own information:</td>
</tr>
<tr>
<td>Sample Business Case</td>
</tr>
<tr>
<td>Sample Privacy Impact Assessment</td>
</tr>
<tr>
<td>Sample Equality Impact Assessment</td>
</tr>
<tr>
<td><strong>Employing organisation</strong></td>
</tr>
<tr>
<td>Employing organisation</td>
</tr>
<tr>
<td>Who will employ the worker?</td>
</tr>
<tr>
<td>Ideally the employing organisation should be non-medical with a holistic care ethos that encourages the HIU Lead to act with freedom, courage and creativity. Some organisations find data sharing an easier process if...</td>
</tr>
</tbody>
</table>
### Infrastructure and processes to consider

| the HIU lead is employed by the Acute Trust but if data sharing doesn’t present as a challenge, the preferred option is a community provider. |

### Service specification

Draw up a service specification that provides clarity on all aspects of the service.

[Sample service specification](#)

### Data sharing

Have you got a data sharing agreement that can be adapted for use?

Agreements across different organisations will be needed, for example between A&E providers, ambulance service, social care, police, GP practices and the High Intensity User service.

[Sample data sharing agreement](#). CCGs should review these in relation to their own confidentiality agreements.

### Communications and engagement with stakeholders

Communication of the new service with a number of groups and other local services will help the service lead introduce the service and create the buy-in and support required.

Involve your communications colleagues early in the process and develop joint communications across your health economy so the new service is communicated consistently and in line with the ethos of the service.

### Communication about the service

Who do you anticipate the service will interact with on a day to day basis?

How will you communicate with them about the new service?

Would it be of benefit for them to help co-design the service?

Services you may need to engage with include:

- A&E
- GP practices and the wider primary care team
- Mental health services
- Drug & alcohol services
- Police
- Social services
### Infrastructure and processes to consider

- Third sector – faith and voluntary
- Community services (community matrons, respiratory teams, falls team etc.)
- Ambulance service
- Jobs centre
- Data analytical services from the CSU or Business Intelligence team at the Acute Trust who will be responsible for providing and evaluating changes in activity.

See Communications and Stakeholder Engagement Overview

### Evaluation and monitoring

Regular monitoring of how the client group is accessing services is vital to identify changes to service use. Be clear about your starting point and what you want to achieve. But don’t over measure - it can get complicated.

**Logic Model**

Develop a logic model to provide clarity on the expected inputs, outputs and outcomes to aid evaluation of the service and understanding of whether it is meeting its aims.

[Sample Logic Model](#)

**Key Performance Indicators (KPIs)**

Agree the KPIs to be used in line with the objectives of the service. Focus KPIs on a 40% reduction in A&E attendances and non-elective admissions and potential 999 ambulance calls.

If quality of life and self-harm reductions can be measured, it would provide a marker of truly improving outcomes providing strong qualitative evidence that HIU patents are not simply advised not to attend A&E any more or that they have just diverted their energy to other parts of the health and social care system.

There are a number of qualitative tools that could be considered including GAD-7 and Recovering Quality of Life (ReQuol) scores along with a measure of loneliness.

If necessary, 999 activity can be gained from A&E ‘mode of transport’ data rather than the need to contact the ambulance service.

### Ongoing monitoring
Infrastructure and processes to consider

How will you regularly monitor the contact the worker’s current cohort of clients has with A&E? Can you develop a facility that allows the worker to see the active list at all times, re-run the report for updates and search for clients by name to review their activity?

It is recommended that a list of the Top 50 A&E attenders are identified every three months on a rolling basis. This ensures clients are current and also provides a relevant baseline for evaluation every three months, post intervention by the HIU lead. It is difficult to measure ‘what hasn’t happened yet’ so until the service is running for long enough to evaluate 12 months pre and post intervention, then the three month method is a good starting point under the assumption that their pre intervention activity would have remained constant if no intervention had taken place i.e. neither increased nor decreased.

Ongoing evaluation

How will the service evaluate performance and report on progress? Is there an opportunity to track the whole population of HIUs with the CCG footprint and not just those receiving the intervention in order to provide a control group?

It is helpful to produce a quarterly board report that provides information on both quantitative and qualitative outcomes. Qualitative outcomes could include self-harm reductions and case studies of real client stories. Clients are often invited to present to the CCG or at events to help lower the stigma associated with this group.

Recruitment / Sourcing the team

Getting the right person in the role is one of the key success factors. This role is not dependent on having someone clinical in post to achieve the results – rather the person employed having the right skills and attributes.

Advert

How can you make the job appealing to someone with high emotional intelligence, resilience and a natural ability to problem solve creatively?

Focus on the attributes and skills of the person, rather than a particular clinical or non-clinical background.

Where can you promote the role to find the right person?
### Infrastructure and processes to consider

Possible places to advertise include the third sector, police, social care, local hospital, drugs & alcohol services, council services such as housing.

Leave the advert as wide as you can to attract the widest possible field.

**Sample Job Advert**

<table>
<thead>
<tr>
<th><strong>Job description</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>The job description will depend on how your service will work to meet your local circumstances.</td>
</tr>
</tbody>
</table>

**Sample Job Description and Person Spec**

<table>
<thead>
<tr>
<th><strong>Selection process</strong></th>
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<tbody>
<tr>
<td>How will your selection process identify the people with the right key attributes for the role?</td>
</tr>
</tbody>
</table>

You will need to ask focused questions around observational and negotiating skills and identify high emotional intelligence and resilience.

**Sample Interview Questions**

<table>
<thead>
<tr>
<th><strong>Contract</strong></th>
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</thead>
<tbody>
<tr>
<td>Who will hold the contract?</td>
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<tr>
<td>How long will it be for?</td>
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</table>

Bear in mind time for the service to establish and see results and the challenges short term contracts pose to staff recruitment. For these reasons, it is recommended to be no less than 18 months.

**Induction**

Are there induction activities that are particular to this role that need to be arranged?

This could include the techniques the service lead will use to engage with this group, opening conversations and how exactly they plan to make a meaningful connection. The induction could also involve linking with key stakeholders (see communications section) such as social services, police, drug and alcohol services, third sector support. This may be best achieved via a workshop format as part of the service set up. Other elements of the induction could include linking with data analysts; discussion about resilience to prevent burn out; care planning; and coaching support.
## Infrastructure and processes to consider

### Identification of client group & access to the service
Good data analyst services are important to ensure the appropriate client group is identified and the service is contacting current high intensity users of services.

The **Caldicott guidance**

For the purposes of Direct Health Care

Patient consent will be gained in order for (hospital) to create reports for High Intensity Users non-elective admissions and share with (host org) (See Appendix 2 1.4)

### Information governance
Consent once obtained needs to be kept refreshed and up to date as time goes by as circumstances and levels of data sharing may change. All IG processes need go through the local data protection office within the CCG or Acute Trust.

Sample GDPR, IG Flowchart, ISA between host and Acute, Individual Client DSA

### How Individuals will be identified
Concentrate on the past three months' highest A&E attenders to use as preliminary baseline data.

Do you have good links with hospital Business Intelligence to identify the Top 50 HIU attenders at A&E?

Do you have other sources of intelligence about vulnerable clients? Links with the police are essential for this and a great resource for resilience.

Key data that is needed at this stage includes: name, NHS number and phone number.

How will future cohorts be identified, when and how?

### Define eligibility criteria
Will you set eligibility criteria? Is the service just for CCG residents?
## Infrastructure and processes to consider

Nationally, the service tends to be aimed at clients aged 18 years and over, within the local CCG footprint and therefore all savings were attributed to the host CCG.

## Practical considerations

<table>
<thead>
<tr>
<th><strong>Location</strong></th>
<th>Where will the worker be based?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Is there a host location where there will be sources of everyday support?</td>
</tr>
</tbody>
</table>

HIU services across the country are based in a variety of host provider settings. The most successful being social enterprises, CICs, Community Providers, Third sector organisations or council settings.

Hot desking and home working are options for some of the week but the worker will be out visiting clients/services for a large proportion of the days. Freedom and flexibility for this role are key to successful outcomes and to meet the needs of the clients. If peer support is available for the HIU leads to tap into, then this is beneficial.

<table>
<thead>
<tr>
<th><strong>Equipment</strong></th>
<th>Mobile phone.</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Laptop or computer.</td>
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<table>
<thead>
<tr>
<th><strong>Documentation</strong></th>
<th>How will the care provided be recorded?</th>
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<tbody>
<tr>
<td></td>
<td>Is bespoke documentation needed?</td>
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<tr>
<td></td>
<td>How will it be shared with others involved in the clients’ care (as appropriate)? Does it need to be?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Communication with the individuals GP</strong></th>
<th>How will you inform the individuals GP that you are working with their patient?</th>
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<tbody>
<tr>
<td></td>
<td>Is there an opportunity to have electronic access to health records?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Hours of operation</strong></th>
<th>What hours will your service operate?</th>
</tr>
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</table>

Nationally, the service is 37.5 hours a week and hours are flexible dependent on what the clients need. Generally, the service operates on weekdays between a minimum of 9am – 5pm. Out of hours on-call telephone contact is not usually part of the HIU Lead’s contract although
Infrastructure and processes to consider

Some remote contact may be beneficial as part of a flexible working approach (see out of yours contingency support below).

“It is useful to have multiple issues presenting at the same time which requires a degree of flexible working, balanced against having a healthy work life and home life. What works well for me is if I send an uplifting text to a couple of clients on a Sunday morning, in order to provide a small piece of positive reinforcement over the weekend when many services are closed. This works extremely well as a way of maintaining connection and supporting behaviour changes without burning out myself.”

HIU Worker

Out-of-hours contingency support

It may be useful to utilise an established out-of-hours provision for this client group, many of whom have unpredictable behaviours that require regular out-of-hours support so the HIU lead can remain 9-5.

Is there a local out-of-hours provider, e.g. volunteer provision, Silverline, crisis team, mental health helpline, Samaritans, that could provide additional support out of hours? Some make outgoing calls to clients to support the role of the HIU lead.

Is there a local Mental Health Helpline, a service that is free to the caller (even from mobiles) and operates evenings and weekends?

Discharge and ongoing support

Many individuals, following initial support from the High Intensity User service are ‘discharged’ without the need for follow up. The term ‘discharge’ is not used with the cohort and it is more like the HIU lead ‘walking backwards’ once individuals are embedded properly into the community.

Experience has shown that talk of discharge instigates feelings of rejected by doing well if they are discharged. It also gives the opportunity for immediate re-referral into the service if they relapse or need a course correction; rather than having to become a frequent attender at A&E in order to regain support.
### Infrastructure and processes to consider

An example is a successful partnership with [Silverline](https://www.silverline.org.uk) who make daily outgoing calls to selected individuals of this cohort to address their feelings of loneliness and to negate the need to call 999 or attend hospital. Another example of outstanding support to promote human connection is [Camerados](https://www.camerados.org.uk) who believe friends & purpose are the two most vital elements to have in life. Works wonderfully for this client group.

Experience at sites has shown that, on some occasions, after about three to six months support, clients can relapse which could lead to the calls to 999 or A&E attendance reoccurring. Right from the outset, the cohort are informed of the possibility of relapse and, the support of the HIU lead as well as open and honest conversations, can prevent a potential relapse or if they do then it has less impact than before. They are picked up immediately and worked with again until stability ensues which tends to be a shorter time than before.

### Support to the worker

Managing this cohort of individuals can be extremely demanding and exhausting, particularly if only one worker is employed, so there needs to be consideration to how to prevent the worker from overload. Adequate training, regular supervision and coaching sessions are an essential part of maintaining the worker’s good health as well as successful results.

<table>
<thead>
<tr>
<th>Clinical supervision</th>
<th>Who will provide clinical supervision to your worker (if they are working as a clinician)? Do you have someone in the organisation or will you need to source this from elsewhere?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coaching</td>
<td>Would the worker benefit from coaching to support them in the role?</td>
</tr>
</tbody>
</table>

1:1 coaching for the HIU lead is recommended from the start of the contract or ‘buddying’ support with other HIU leads across the country with whom they can share learning, experience and how to overcome challenges faced.

<table>
<thead>
<tr>
<th>Training</th>
<th>What training will be needed and how will it be provided?</th>
</tr>
</thead>
</table>
Infrastructure and processes to consider

In order to provide clear direction, maximise success and begin managing clients as soon as possible, training is recommended in the fields of:

- learning the techniques used to change the behaviours of complex clients;
- staff resilience to prevent burnout;
- how to identify and connect with essential services; and
- how to deliver telephone coaching to clients.

“This scheme fills the need for people with chaotic lives – there is a small minority of people for whom the system is too rigid for their needs and the ‘rules’ of the system don’t work for them. They fall through the gaps in service and their health outcomes and quality of life are poor as a result.”

Commissioner

8. Conclusion

This resource pack was developed to share NHS RightCare’s national experience and to offer support to other areas interested in the service. It is not intended to be exhaustive or prescriptive. We hope you find it useful and once again, many thanks to the 80+ CCGs that are live with the programme so far for sharing their expertise and resources.

If you have experience to share regarding a similar service or following the use of this pack, please do let us know so we can learn from each other.

For more information about NHS RightCare go to:
www.england.nhs.uk/rightcare

Email: rightcare@nhs.net
9. Appendix - Rhian’s approach

Rhian, the National High Intensity User Lead for NHS RightCare, explains the way she approaches her contact with clients.

“It all starts with a phone call and a simple opener: “Hi. My name’s Rhian; I work on behalf of A&E and I’m really worried about you. I notice that you have been to the hospital lately and I was wondering what’s happening in your life and whether you can be better supported. Is it a good time to talk?”

“This is usually enough to get people starting talking and I actively listen for around 20 to 30 minutes. I take care not to interrupt and I reflect back what they are saying to see if I have grasped the full extent of the problems faced or issues in their lives. It is surprising how many people say it’s the first time they feel they have been truly listened to.

“Once they have had time to fully vent and talk about what’s important to them, I then ask: “The journey you have just described to me about going in and out of hospital, having conflicting advice because you’ve seen many professionals with different ideas about what is happening, do you feel this is working for you now, or would you like to try something different?” If they say yes (and all have), then I ask if I can come and meet them the very next day. I always make initial contact on a day when I know I am available to go out to them the next day. Whilst still on the phone, I ask them if it’s ok for me to begin working together with other agencies like housing and their GP to act on what we’ve just highlighted as the main issues to tackle first – this acts as a verbal agreement to approach other agencies in advance of them signing an individual data sharing agreement.

“As a lone worker, personal safety is obviously very important. Based on a risk assessment, I have a number of options such as meeting in a neutral place, taking an ununiformed escort and I always check in and out of the visit with someone from my office. I also call the client on the way to the visit to check out their current state of mind, whether they are actually at home and find out if anyone else will be there at the visit. This is really helpful information and creates another good connection. If someone I don't know is there with them, I may suggest we go out for a walk instead of meeting at their home.

“Once I get to their home or wherever we have agreed to meet, I introduce myself and spend around 30 minutes finding out more and trying to make a connection between us. My approach is always to build on their strengths and the positives, to create new conversations and introduce creative ideas, rather than correct their weaknesses. I always try and leave time for immediate positive action – if we have an idea of something new to try or somewhere to go – then we do it there and then if we can – I like to take them by surprise, act on impulse. These activities usually involve human connections – connecting the person with an activity they enjoy, a
person who could help them, an opportunity to volunteer or just laugh with similar minded people. Where I can, I phone ahead to wherever we are going so the client gets an extra special welcome when we get there and they are primed to connect with them yet as naturally as possible. Many agencies are aware of what this service aims to do so they are extremely supportive to receive new people into their organisation or community in this way. They see how well it works.

“At the first face to face contact, the client signs an individual data sharing agreement. I approach this by explaining that I need their permission to explore the ideas we discuss and to help support them better so that consent is informed.

“After the initial visit, most of my contact with clients is by phone. I explain that I am there to support them and give them my phone number so that they can text me or give two rings (if they have no credit) and I will call them back. Often this acts as their ‘life line’, an alternative to thinking that going to A&E or 999 is the only answer. This switch is immediate, hence a sharp turn around on the times they call 999 or attend A&E.

“Before we leave each other on this first visit, I check it is OK if I call the next day and find out what time is best – this gives them some control so the relationship is balanced. Then I make sure I call them at that time – it’s so important to only commit to what you can do so they don’t feel let down or that you are too busy with other people to put them first.

“The next day, I call at the agreed time – it doesn’t need to be long phone call, maybe five minutes. I usually try to give them a piece of extra information – mention something I’ve seen on the news or tell them something positive that happened to me that day – something and nothing really that may prompt a conversation or widen their thinking and take the pressure off them making the conversation when nothing from the day before would have changed in their lives. I never ask how they are or ask what they are doing today. If I can, I mention a common link – perhaps asking how their pet is or an interest they spoke of when we met.

“I may mention something I am going to do that day – perhaps take a walk – and ask them if they will do the same – sometimes I may ask if they want to come with me on my walk if they are struggling. Then I always try and end the conversation in something of a positive way and add balance – I don’t want it to be always me calling them and want to quickly transition to a point where they recognise their tipping points and start calling me pre-crisis.

“I may have contact with a client every day for a few days, trying to put the onus on them to contact me, then reduce this down to every two days. What is important is that they call me when they feel they need to go to A&E. We discuss the triggers that make them feel that way, how to recognise them and then to call me or the
mental health help line number we use, instead of going to A&E when the trigger arises.

“It soon gets to the stage when clients are contacting me every two to three weeks and it’s very much about coaching them in short phone calls – 10 minutes max. Most are trying to get to the point where they have purpose in life and friends. I want to help my clients to flourish and also accept that some won’t in the way we set out in the beginning. It’s really important to set your own expectations over what can be achieved and have resilience and flexibility to go with the changes this group throw up.

“Contact with each client usually lasts over several weeks with some requiring longer. I’ve learnt to not discuss being discharged – this tends to have a really negative effect. Instead, I let the contact seemingly fizzle out in the respect that they are connected to other members of the community and not just me. I then keep an eye on their ongoing contacts behind the scenes to check they are still on track. My sign of success is when they contact me at their tipping point.

“This is my approach and others may do something different. But using this method, I have seen results really quickly – within a few weeks of getting in touch. We have been successful in reducing A&E attendances, non-elective admissions but more importantly, making a really positive impact on this cohort; an extremely vulnerable and lonely group in society.
10. Appendix 2 – Information Governance

10.1 IG Flow Chart HIU Programme

Information Governance Flow chart High Intensity User Programme

Information sharing agreements set up between acute trusts and provider

↓

BI departments at Acute trust send data spreadsheet with details of the top 50 frequent attenders of A&E within the past 3 months to the HIU Lead (provider) via secure email

↓

HIU Lead (provider) will look at the list and identify 15 individuals to support for the following 3 months

↓

HIU Lead will then make contact with the identified cohort over the next quarter to offer/provide support. To include at least one face to face whereby a consent to share information agreement is completed with individual ↓

After the first quarter the HIU Lead will send a list of NHS Numbers, date support started and confirmation of agreement to share information back to the BI Team at the acute trust and ask them to compare this to the data to the previous quarter and continue to track the individuals every quarter thereafter

↓

Towards the end of each quarter, the HIU Lead will then ask the BI Team at the acute trust to send over an up-to-date list of the top 50 frequent attenders for the previous 3 months (from that point in time) so they can identify a further cohort of around 15 to work with, whilst evaluating the activity of the existing individuals on the programme

↓

HIU lead (provider) will have quarterly contract monitoring meetings with the CCG to feedback on outcomes both qualitative (case studies) and quantitative (data outcomes)

↓

HIU Lead sends over the rolling cohort to the BI Team every Quarter and the BI Team send over the monitoring of this plus the new cohort Note: The BI Team could either be the Acute Trust or the CSU.
The collating provider has primacy, and must have/had a direct relationship with the patient.

CCG COMMISSIONS HIU

COLLATING PROVIDER: A&E BI TEAM CSU SERVICE (HIGHEST CONVEYANCE RATES) OR GP (HIGHEST ADMISSIONS)

CONTACT MADE BY COLLATING PROVIDER & THEY OUTLINE THE PURPOSE FOR THE CONTACT, AND EXPLAIN THE HIU PROGRAMME

HIU MAKE CALL OR HOME VISIT WITH 24HRS TO GAIN CONSENT FOR CONFIDENTIALITY PURPOSES

FURTHER CONTACT MAY BE NEEDED TO BUILD RAPPORT AND OFFER SUPPORT

COLLATING PROVIDER TO PROVIDE TOP XX ATTENDEES FOR LAST 3 MONTHS. ONLY NAME AND PHONE NUMBER REQUIRED.

PATIENT MUST HAVE ABILITY TO CONSENT AND IT MUST BE FREELY GIVEN

CONSENT TAILORED TO PATIENT ALLOWING ACCESS TO RELEVANT INFORMATION FOR HIU PROGRAM.

Consent must be three things under GDPR:
1. Specific – Specifically what is necessary for the HIU programme and not more than minimum requirement.
2. Informed – What data is needed? Why? Who will see it/out it? (Fair Processing).
3. Freely given – Must be a genuine choice and be just as easy to withdraw. No pressure i.e. service withdrawal if consent not given.

The above are secondary to the legal definition of consent under GDPR. Please consult your D.P.O.

This can be withdrawn by individual at any point, details on how to do this are on the initial consent form.
Participants can also tailor their consent (i.e. no police contact/access to personal records) this is documented and the patient re-signs the consent form to reflect this.
If the patient wishes to withdraw completely their information is removed from the HIU program.
Consent override is not required in this case. Individual cases can just be removed from the system by HIU lead.

We recommend you seek advice from your D.P.O (Data Protection Officer) when establishing the process for accessing or sharing any data that could be considered sensitive. Particularly after the introduction of GDPR in May 2018.
Regulations to Consider.

- **General Data Protection Regulation** – GDPR provides specific Processing Conditions for Healthcare. Users need to be informed about what happens with their data and by whom.

- **Common Law Duty of Confidence** – The sharing of patient information beyond direct care, or with organisations a patient wouldn’t reasonably expect their information to be shared with, requires either patient consent or a statutory override to comply with. Processing Conditions (except consent) would not give you this.

- **The Right to be Forgotten** – Where processing personal and/or sensitive personal data about individuals under consent, they also have the right to be forgotten and right to restrict processing under GDPR. If these rights are exercised, information use must be restricted or disposed of. There are some examples where this right can be waived, such as for exercise of legal duties. For healthcare however, unless there is a public health issue or other issue covered by statute (such as communicable diseases which is covered by Reg. 3 of the 2002 Control of Patient Information Regulations), the right to be forgotten must be applied. Even if it is not necessarily in the patient’s best interest, if they have capacity that right must be respected.
CONSENT FORM FOR DISCLOSURE OF INFORMATION

Name…………………………………………………………………………………………
……………………………………..
Address………………………………………………………………………………………
…………………………………………………..
Post code ……………………………………

• I give permission for (Provider), my GP practice and the local constabulary to share personal information with other service providers in connection with my care.

• This includes accessing and sharing my medical, and if applicable mental health and police records.

• I agree to referrals being made to the mental health helpline, 111 or other service providers that may be relevant, in order to support my needs.

• I understand that (provider) may obtain information about me from the various partner organisations (which will be explained to me) and as such my rights under the Data Protection Act will not be affected.

• I can choose to withdraw my consent at any time.

Signature of client………………………………………………………………………………………

Printed name:
……………………………………………………………………………………………

Date:……………………………………………………………………………………………

Signature of HIU Professional:
……………………………………………………………………………………………………

Printed Name:…………………………………………………………………………………………

Date:………………………………………………………………………………………………
10.4 Information Sharing and Processing Agreement MOU

Information Sharing and Processing Agreement for (Hospital) and (Host Org)

Memorandum of Understanding

This Memorandum of Understanding (MoU) defines the arrangements for the sharing and processing of data between (Hospital) and (host org).

The appendices provide further information and guidance should this be needed.

1. Parties to the agreement: Full name and address of the organisations or businesses.

<table>
<thead>
<tr>
<th>Hospital Name &amp; Address</th>
<th>Host organisation name and address</th>
</tr>
</thead>
</table>

2. Why is the information being shared/processed?

To support the delivery of Direct Patient Health Care provided by (host org) through access to (Hospital) paper and electronic patient health records.

This agreement replaces previous versions issued....

3. What information is being shared/processed?

1. Accident and Emergency Department attendances (through system interfaces and feeds)
2. Health Record storage areas at (hospital)
3. Reports of High Intensity Users (Frequent Attenders) in the A&E Department and non-elective admissions to (hospital) wards – following patient consent.
4. Patient information from Care Coordination service to Extensivist service and Care Home Team/Project.

Information flows are outlined in Appendix A

4. Where is the information being shared/processed being held?

Within Alert, PAS, Adastra, Software of Excellence and the reports are held on secure drives within the two service providers.

5. What is your legal justification for sharing? Has consent been gained if required?

For the purposes of Direct Health Care

Patient consent will be gained in order for (hospital) to create reports for High Intensity Users non-elective admissions and share with (host org).
6. How will the information be shared? (e.g. data transfer – include any security measures)

- Electronic data transfer – Information accessible via (hospital) Department Information System, Alert and (hospital) Patient Administration System (PAS) created through (hospital) interactions with the patient.
- Physical access added to identification badges.
- Secured email for sending HIU reports
- Access issued to SoE for staff
- Secured email for Extensivist and Care Home Project
- Secure email and fax i.e. DNACPR forms

7. How will responsibility for the shared / processed information be attributed?

For current and future patients / clients, Data Controllership will be the responsibility of the service provider.

The (host org) will indemnify and compensate (hospital) for any loss (financial or otherwise) that is sustained due to any failure by them – including their employees or sub-contractors – to act in accordance with the terms of this agreement and relevant legislation.

- Any information security incidents involving (hospital) data (e.g. potential breach of Data Protection Act 1998) are reported to the Information Governance Department at (hospital) and the incident must be logged and investigated.
- Appropriate disciplinary action to be taken, should ant employees and those working for, and on behalf of, and on their behalf, fail to comply with the terms of this agreement and relevant legislation.

8. How will the information be stored? (e.g. secure server – include any security measures)

Both organisations use secure UK based servers for storage purposes.

9. Who will handle the information?

- (host org) Front line administration staff
- (host org) Urgent care shift supervisors / staff
- (host org) Head of Urgent Care (line manager to service lead)
- (host org) Chief Executive Officer
- (host org) High Intensity User Lead, who may then share this information with:
  - (host org) Care Coordination team – through Adastra and Emis Web
  - NHS 111 team – through Adastra special patient notes
  - Local Ambulance Service – through discussions with clinicians over the phone e.g. Care plans
  - GP practices – through Emis Web, Secure email

With patient consent, (host org) also pass information to:
- Police
- Social services
- Local council i.e. social care, housing association
- Third Sector organisations

- (hospital) Unscheduled Care Divisional Analyst
- (hospital) Extensivist team – by (host org) third party.
- (hospital) Care Home Team - by (host org) third party.
10. How is access controlled?
There has been documented evidence produced to confirm that both service providers will inform each other to ensure access is terminated for leavers via the appropriate process. This is in place for: (host org) to (hospital) – Alert, IT Network access, Smartcards, PAS ID Badges, SoE.

11. What training is provided?
- All staff who have physical access to the hospital site are appropriately trained by the Medical Records Department at (hospital) including basement training / IG talks etc.
- New starters have an induction and sign up to a confidentiality code of conduct.
- New starter complete the mandatory online Information Governance Introduction to IF course.
- All staff who have access to PAS or Alert are trained by (hospital) IT Training Department.
- (host org) staff training records are recorded by (host org) using a training matrix (HISS? PAS and Alert may be recorded with (hospital) also)

12. How long will the information be kept?
Each organisation will, as Data Controller for the information they hold, be responsible for it’s appropriate retention and disposal, both agree that such decisions will comply with:
Records Management, NHS Code of Practice, Part 2
Second edition (January 2009)

13. How will information be destroyed?
As above (section 10) and in accordance with:
Destruction and Disposal of Sensitive Data
Good Practice Guidelines, currently version 3.0, Date March 2015

14. What date will the information be shared? Initial date must be later than the date of the signatures below and should give an indication of subsequent dates for regular sharing.
Information will be shared with effect from the date of signature.

15. What are the names, roles and contact details of any members of staff who will make sure that the required information is shared at the appropriate time?
16. When will this agreement be reviewed and by whom?

<table>
<thead>
<tr>
<th>On behalf of (hospital):</th>
</tr>
</thead>
<tbody>
<tr>
<td>(name)</td>
</tr>
<tr>
<td>IG Manager</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>On behalf of (host org):</th>
</tr>
</thead>
<tbody>
<tr>
<td>(name)</td>
</tr>
<tr>
<td>IG Lead / SIRO/ Risk Manager</td>
</tr>
</tbody>
</table>

(Hospital) reserves the right to withdraw access to the information set out above at any time without notice if it believes the agreement has been compromised e.g. unlawful use of data, insufficient security breaches of confidentiality.

This agreement must be formally approved and signed by both parties before any information sharing takes place. Both parties will ensure that the ISA and any associated documents are known and understood by all staff involved in the process.

**Originating organisation**
Name of organisation: (hospital)
Name: Position: (Caldicott Guardian)

Signature ...........................................Date:.................................

**Partner organisation**
Name of organisation: (host)
Name: Position: (Caldicott Guardian)

Signature ...........................................Date:.................................
11. Appendix 3 – Case Studies

“I have seen around 50 professionals over the past 2 years; social workers, psychiatrists, nurses, occupational therapists, psychologists and my P3 link worker is the first person to fully understand my needs.” Client P

“When we go to their home, it’s not a social call. We know, and they know, what the purpose of the visit is. It helps them to have a focus, and it helps us to be able to show them that we will do what we said we would”. Provider view

“The service user is on a journey and we are on it with them. The professionals in MDT aren’t just there to get first steps, we support them along the way, and we find tools to help them back up if they fall.” MDT member

The role of the Link workers at the meeting is seen as of central importance in that “they are able to bring service users stories to life – tell their story in a way we may not have heard or thought about before.” MDT member
Case studies from HIU Leads across England

“I was thinking I was just going to keep getting things wrong until I died”
Kevin was young, with severe mental health problems, addiction and low cognitive function, and was exploited by street gangs who took his medication and left him to suffer multiple epileptic seizures.
The HIU workers were the only ones able to track him down and support him to engage with services until he made the successful move to a Residential MH care home.

The following are two examples of the contribution the service can make to individuals’ lives. The provider in these cases were British Red Cross.

Michael
Michael was referred to the HIU service after a period of ill-health left him lonely and lacking in confidence. Michael expressed an interest in fishing, but when British Red Cross (BRC) contacted the local fishing club they found that it was about to close, as the ageing members of the club were unable to keep the pathways and ponds clean and fit for use. BRC was able to encourage two young people who had also been referred to the service to volunteer to clear the pathways and ponds in return for fishing lessons. Michael now teaches fishing on a regular basis to new club members. The fishing club is thriving once more and will continue to offer support and volunteering opportunities long after BRC’s HIU support ends.

Annie
Annie, aged 86, attended A&E regularly as she was struggling with the loss of her partner and having to move from the home they had shared together. She was also having breathing difficulties. After being discharged from A&E, British Red Cross (BRC) took Annie back home.
During the journey Annie did not talk to us a lot, and when we arrived back to her apartment and commented on how beautiful and clean her new supported independent living accommodation was, she shook her head and was almost in tears. When we asked what was upsetting her, she answered: “No-one listens to me”. Annie had support from her family, especially from her grandson, but Annie felt they were not able to listen to her and that she could not express her views anymore. BRC offered to visit her as part of the High Intensity User service which she gladly accepted. Annie disclosed she was feeling very low and depressed and didn’t want to burden her family who felt she should be happy in her new apartment and would rather be in hospital than on her own in her apartment – the crux of her frequent attendances.
BRC supported Annie to move to a different flat on the ground floor where there is more hustle and bustle, rather than the 2nd floor where she felt physically isolated. To make sure Annie has access to some more long-term support BRC referred her to a befriending service which will provide on-going support once BRC’s visits come to an end.
Four weeks on from when we first met Annie and things are falling into place for her now. She is more positive and her confidence has grown greatly, particularly on weekends when her family are busy. Since receiving our support, Annie has not been readmitted to hospital nor visited A&E.
What other people tell us

“You’re the first person I have trusted for a long time, thank you”

“I really didn’t think there was a way out from where I was and what I had become. Thanks!”

“I don’t know how I would have changed my negative attitude, low mood and poor motivation without the consistent support from Toni. The level of input provided inspired me to change”

“Emma restored my faith in services that I felt didn’t listen and understand, with guidance I re engaged into services I desperately needed and formed positive relationships that have continued”

“I have seen around 50 professionals over the past 2 years; social workers, psychiatrists, nurses, occupational therapists, psychologists and Frank is the first person to fully understand my needs”

The following is an example of a lady who presented only with high risk medical complaints that has been supported by a non-medical HIU Lead with astounding results.

**Joanne**

In the 3 months prior to Natalie’s engagement, Joanne had 17 ambulance call outs, 13 conveyances to ED and 5 admissions to the Intensive Care Unit. Since engagement, Joanne has had no ambulance calls and no admittances. Joanne has also lost 8lbs in weight through her new love of exercise and her health has dramatically improved.

Joanne is no longer dying, she is connected.

**This is how it was made possible……**

Joanne presented with acute brittle asthma, frequently calling ambulances with ED admissions resulting in five stays in intensive care in a 12-month period. Joanne at our first chat started off with only speaking of medical issues but soon turned to everything else that wasn’t going well in her life. The HIU Lead Natalie discovered Joanne felt that she was a burden to her family; that they would be better off without her; that all they did was worry about her; that her kids should be able to stop worrying. She was not managing her brittle asthma at all - in truth she said she was slowly committing suicide via the mismanagement of her condition. She had disengaged from her GP, mental health and breathing support as in her words “they all tell me I’ve got mental health issues”. Joanne never left the house on foot and only rarely took short trips in the family car. Her husband is her carer. Joanne was also lonely, she used to have a much wider social circle but had lost all contact over the last few years.

Joanne adores her boys who are her life and she would do anything for them. Her face and voice light up when chatting about them.
She had lived a childhood full of neglect and abuse so is there any wonder the kindness of strangers in the form of paramedics and our NHS was so important to her?

After meeting her for the first time, Natalie encouraged her to walk to school the very next day to collect her youngest. Natalie rang the school (with consent) to let them know things were a little tough, but she also asked that when Joanne arrived could they please treat her like a queen and welcome her like an old friend. Within a week Joanne was walking daily to school and had made friends with people on her street. School also set up informal support for her youngest child.

Natalie attended her upcoming Consultant appointment with her and helped her chat about what was important to her and encouraged her consultant to look with fresh eyes. She was keen to have a medical procedure as she saw this as a way to help her fix her health. The professionals were not keen but agreed to seriously consider it if she was engaging with me.

Joanne also began attending her sons Taekwondo and in the coming weeks she expressed an interest to join but she lacked the funds to pay for the kit and membership. Through her social prescriber based at her GP we secured the funding; this also linked her positively back to her GP surgery. She could now join her son in the weekly lessons, something they had dearly both wanted.

Joanne was soon attending Taekwondo twice a week, a supportive group where the instructors understand Joanne’s needs and don’t let her push herself too far but encourage her to do just a little more. She trained really hard and at the end of March she had her first grading and passed with just one mark off a distinction! This was just 9 weeks after our first contact. Joanne used to go with her son, he has changed his mind, but Joanne still attends every week without fail.

Joanne has also invested in a step machine and an exercise bike so that she can improve her fitness and learning new Korean words and numbers. She has begun to speak to her GP again about her mental health as she now recognises that this is a factor and it’s just another part of her health. We have talked about lapses and relapse and she recognises now that she needs to manage all of her health. The trust we built very quickly and the chats about how we are amazed with how she has made it this far in life have built her up. She knows that she will have bad days and even then, she can call me so that things do not go back to how they were.

Joanne has recently attended a psychiatric assessment to help with her low mood and bad dreams. He has tweaked her meds which have levelled her, I am encouraging her to now seek therapy as the time is right to talk. She has had some mental health wobbles, but instead of burying her head in the sand she called the mental health helpline. Again, using appropriate pathways for the first time in a long time.

Joanne now has things to talk about with her husband as they are not always in together; he is proud of his wife and treats her to reward her also. For a lady who felt like she was a burden, to now feel her husband’s pride is huge.

Joanne has made friends in her group and on the school run, she is amazed they really like her.

She has also been looking after a friend’s dog and doing short walks, now she wants her own poodle, as they are less likely to upset her breathing.

The impact on the NHS is the huge cost saving in ambulance conveyances, ED attendance and non-elective admissions to ICU and the wards.
The impact to Joanne, she is alive and in a far better physical and mental state than just 2 months ago.

**Joanne quotes:**

“Me and my husband have more to talk about.”

“Natalie - I couldn't have done any of this without you, my life has changed so much”

“Thank you sooooooo much for everything and making me feel so much better. You’re such a delightful person to talk to”