

INNOVATION & DEVELOPMENT FUND
PROJECT PROGRESS UPDATE





“I started working with this tool as part of a pilot scheme in September 2014 and I have been and still am, very pleased to have been involved. We have completed roughly 10 so far and I hope we continue to have the opportunity to do more.

The service users who I have completed the advocate tool with have all felt that it is valuable to them. People get as involved in the form as much as they feel they can at the time and this can vary for each person and at each meeting. There have been some occasions when I have learnt a great deal about the person I have been doing this with.

There has already been one occasion when the tool has been put to good use. i.e. when someone was not able to say where she wanted to go when she was in crisis but we could refer to The Pocket Advocate for the information.

This tool is inspirational and people feel really invested in it as it is designed by, completed by and used by the person themselves - I am the person who assists them with the practical task of the form itself. They are in the driving seat, it is truly service user led, and for this I think the tool is a unique and invaluable tool.

It's a bit like a mobile phone - once you have one you wonder how you ever lived without it. “

Moira Matthews - Social Worker

South Camden Rehabilitation & Recovery Team

July 2015



Anonamous
Feedback from participant
July 2015

Outcomes, Measures & Outputs

This is where we would like you to assess your progress on delivering each of your agreed outcomes. We would expect to see a range of hard & soft measures under the indicators section, appropriate to each outcome. What key outputs will help you to deliver the outcomes and which have you achieved so far?

Outcome 1

Individuals with mental health conditions are supported to evaluate, assess and manage their condition.

Outcome 1 Indicator

Feedback from the individual. Format to be developed around ability to: recognise signs of distress & appropriate action, access services & treatment, number of hospital admissions, drug compliance.

The Pocket Advocate Online Software & The Pocket Advocate Tool

The Pocket Advocate Online Software navigates a user through a series of online exercises. The nature of these exercises encourage an individual to explore and consider:

- Personal Details & Medication
- Contacts & Support
- Triggers
- Early, Intermediate & Late Signs
- Early, Intermediate & Late Intervention

Early, Intermediate & Late Intervention these sections give the individual the space to assess and instruct themselves and others as to the management of the various stages of their condition. Below are some examples of instructions taken from The Pocket Advocates of participants involved in the pilot so far:

"Regular visits from healthcare professionals..."

"Helpful to come round and see me, but do not want to talk about hospitals."

"Need to phone help."

"talk and listen about other topics as well as the illness."

"Present The Pocket Advocate to me."

"Need to be kept calm. Talking, counselling. Having my own space..."

"Reduce workload/stop work..."

"Call my CPN...help with washing properly, found Crisis Team really helpful (one call a day and came round every other day)."

"Make a plan, giving me permission..."

"Asking for support is difficult but will do it with help of [name]. Reassuring, consider crisis house, support to take meds, eat and personal care"

"CPN to check if I am following my treatment plan. Support to access medication. This is the most important intervention at this stage."

" Writing in my journal and challenging my thoughts. reality checking with people. I may contact Mental Health Service for an appointment."

"I need to go to hospital. I may not tell people the whole truth and may not disclose my thoughts. On my 2 suicide attempts I had been seen by mental health professionals the day before."

"Seek advice, avoid stress, reassurance, grounding, reality checks, being around people reduces voices, good sleep pattern"

"Contact care coordinator and Mum. Spend more time with family. May not feel hungry and will need support to keep a good diet. Clinic review."

"Increase dose of medication, contact mental health team..."

"Talk to Mum and see if case to disturb [CPN]..."

"I need more help. Crisis House or Crisis Team. I may need hospital admission. I may not trust the people who care for me."

"I need to see if it passes, it's a glitch. Can I concentrate on something else and work myself out of it?"

"Once on medication [medication details] I improve rapidly."

"I would go to hospital with my Mum."

"Family to help, provision and prompt with food, and personal care. Contact [Psychiatrist], [care coordinator]. Consider crisis house."

Outputs achieved

See attached anonymised copies of completed TPAs.

Narrative : What progress have you made towards your stated outcomes?

The anonymised Pocket Advocates clearly show that the individuals involved in the pilot have been supported to evaluate, assess their condition. In order to evaluate the overall impact on the ability to manage, we would need to assess each individual over time in regard to: medication compliance; reduced or increased hospital admissions and reduced or increased contact with MHT. The feedback we have had to date confirms that of those who have participated in the pilot, none have been readmitted to hospital. One individual experienced crisis, but was able to manage it and avoid hospital, much to the welcome surprise of her care coordinator.

Outcome Progress Status

green

Challenges

Time Restriction

The pilot began later than anticipated. We hoped to have a minimum of 20 users participating in the pilot. Due to the limited time frame we only managed to reach 10 users. This has also affected our capacity to measure the long-term impact of the individual's ability to self-manage.

Font Size

A general comment from those leading the pilot was that if an individual wanted to go into more detail they were restricted. The solution to this was to refine the design of The Pocket Advocate by reducing the point size of the type used. By doing this we were able to provide participants with more space to feedback their responses.

Date of Issue

This feature was suggested by the pilot team as essential to those treating the individual who may

not have had any previous contact. By including the Date of Issue The Pocket Advocate validates the historic time at which the information refers to, this was deemed of particular importance in regard to the medication and doage disclosed within the document.

Disclaimer

This piece of text was added to confirm that the user took responsibility for the information disclosed within The Pocket Advocate.

Outcome 2

The individual's support network (both personal and professional) better understand the individual's condition and what personalised support they require at different stages of their condition.

Outcome 2 indicator

Feedback from members of individual's support network. Format to be developed around: changes in approach to the individual & their diagnosis, confidence in the ability to act in partnership with the individual.

Evaluative Tool 2

This questionnaire was devised for those supporting the person participating, whether as a professional or member of their personal community. The aim of these questions are to ascertain if and how The Pocket Advocate has engaged the user and their community. The questions and answers given are as follows:

1. Do you have a better understanding of the personalised care required?

Could you give an example of how The Pocket Advocate has helped you to do this?

"Yes - He talked about his care needs more fully."

"No - We already had a good understanding of how things are."

"Yes - We talked in depth about her crisis, intervention and signs."

"No - The understanding is very good already as her career is an advocate for carers rights in Camden."

2. Has your approach to the individual changed since using The Pocket Advocate?

If so, how?

"Yes - I understand 'his' illness more and the sheer extreme of his anxiety when unwell."

"Yes - I have even more respect for her and her strength."

"Yes - I have even more understanding of her complex mental health issues."

"Yes - I have even more respect and understanding of their issues and mental health condition."

3. Has there been any change in your attitude towards their diagnosis?

If there has been change, could you tell us more?

"No."

"No."

"Yes - I have more understanding of the specific situation."

"Yes - I wouldn't say my attitude as much as my knowledge of...she has said very little about her condition before as she finds it so hard to talk about."

4. Do you feel more or less confident about working in partnership with the individual?

Would you like to say more about this?

"Yes - I think it has given us both some understanding and trust and it is only recently we have been working together so this is important."

"Yes - We do work well together but this should make it easier for both of us to express her needs."

"Yes - more confident as I know more about her and her about me."

"Yes - I feel we know one another better and have been through an important process."

Outputs achieved

See attached copies of Evaluative Form 2.

Narrative: what progress have you made towards your stated outcomes?

Copies of the above tool were supplied to those involved in implementing the pilot. The completed tools gave a useful insight into the engagement & responses of the individual's support network in respect to The Pocket Advocate.

Outcome progress status

amber

Challenges

Due to a limited amount of time available to the pilot team not all of the final sessions were evaluated using the above tool.

Until now the project has been unable to offer facilitating organisations evidence of its efficacy, impact and worth. Perhaps the overall incentive has been diminished by this. The project has thus far relied on the dedication, enthusiasm and support of a small group of facilitators who have volunteered to take the time to implement the pilot.

The suggestion to 'humanise' and simplify the questions was taken on board and remains. This remains to be adjusted.

Outcome 3

Individuals are empowered to take ownership of their condition and effectively communicate their needs and requirements to others

Outcome 3 indicator

Feedback from individual in relation to changes in their attitude towards their diagnosis & ability to manage & how supported they feel. Format to be developed.

Evaluation Form 1

Two evaluative forms were devised and included as part of The Pocket Advocate Online Software. These ask identical questions in regard to the individual's confidence and ability in managing their condition. They are placed separately at the beginning and end of the program to register any changes as a consequence of the service. The format of these questions are as follows:

Please answer the following questions based on how you feel right now.

Choose between 1 = least true, and 10 = most true.

- 1. I feel confident managing my mental health needs.**
- 2. When I feel unwell I am able to communicate my experience to family and friends.**
- 3. When I need extra support I contact someone from my mental health team.**

Evaluative Tool 3

The following questionnaire was devised for the individual participating. These questions were designed to ascertain if and how The Pocket Advocate had engaged them:

1. Have you used the Pocket Advocate?

If so, how frequently?

2. In what situations have you used The Pocket Advocate?

3. Have you used The Pocket Advocate to communicate your needs to others?

If so, who have you used The Pocket Advocate with?

4. Have you noticed any change in the way others approach you?

If so, how?

5. Since using The Pocket Advocate do you feel more supported?

If so, would you like to give us an example?

6. Do you have more or less understanding of what you need to do to take care?

If so, could you tell us more?

7. Has there been any change in your approach towards your diagnosis?

If there has, could you tell us more?

**8. Do you feel more or less confident using The Pocket Advocate to assess your needs?
If so, could you give an example of how?**

Outputs achieved

See attached completed: Evaluation Form 1 & Evaluative Tool 3

Narrative: what progress have you made towards your stated outcomes?

We refined this tool heavily in response to the feedback we received from the pilot team. The most significant comment was that this area of evaluation was not something that could be assessed immediately but rather after an individual had some time to use and implement their Pocket Advocate. We plan to organise a focus group in the coming months to give users the opportunity to feedback the long term impact of The Pocket Advocate.

Outcome progress status

amber

Challenges

Evaluation Tool 1

The original version of Evaluation Tool 1 consisted of 14 questions. It became clear after several months that this was too lengthy and therefore impractical. The healthcare professionals leading the pilot reported that often a participant found this process too taxing and as a consequence the answers were understandably rushed through and not given much consideration.

In response to this feedback we reduced the number of questions from 14 to 3. Instead of an answer scale between 1 - 10 (least true - most true), we implemented a simplified 'Yes' and 'No' answer option.

After several months the feedback from this was that the 'Yes' and 'No' answers were too broad considering the potential expanse of an individual's experience. Instead the answers needed to reflect how the participant felt at that moment. In response to this feedback we changed the nature of the tools instructions, clearly stating that the answers to the questions should reflect how the individual felt in that moment and from a scale to 1 - 10 (least true - most true).

Unfortunately the data relating to the final evaluation forms, placed at the end of the process, were lost due to technical issues. So, to date we only have the forms that were completed at the beginning of the process. This information will allow us to register how the participants felt before they began their Pocket Advocate journey.

Evaluation Tool 3

This evaluation tool was not completed. The general response was that the nature of the questions could not be answered immediately after completing the online process and were better placed after an individual had the opportunity to integrate The Pocket Advocate into their daily lives. We plan to organise a focus group that involves those who participated in the pilot and register the more long term impact The Pocket Advocate has had. Ultimately this outcome can only be measured over time.

The other feedback we had for this tool was that in its current form it may be too much of an effort for some individuals to complete given the extent of their ill health.

Of the 10 participants of those who have completed The Pocket Advocate process **none** have been re admitted to hospital.

Other Forms of Assessment

Postcard Feedback

Project Embrace asked facilitators to give participants the opportunity to feedback a more general response to the process of creating The Pocket Advocate. We did this by supplying postcards to facilitators with the hope that participants would feel inspired to share their experience.

1 completed, see attached.

Regular feedback meetings with facilitators

We met with the facilitators regularly to discuss the progress of the pilot and how it could be refined to improve the experience for both the facilitator and participant.

10 meetings in 10 months.

Some of the feedback deduced:

- Evaluative Forms
 - to take into consideration the limited time given to healthcare professionals.
 - to consider the varying ability of those participating
 - questions to be humanised
 - questions to be simplified and perhaps reduced as some are similar and repetitive
 - Evaluative Tool/Outcome 3: combine questions 2 & 3
 - reduce Evaluative Tool 1 from 14 questions to 3

- The Pocket Advocate Design
 - provide more space to allow for more detail they were restricted. Reduced the size of the type used. Particularly in the 'medication', 'physical/medical', 'medication during crisis', 'action & response sections.
 - include date of issue to give medication and dosage historic reference.

- Provide clear promotion for the pilot team to bring more staff on board. That this can be circulated electronically via email.

- Provide clear promotion for potential participants.

- Instructional manual
 - include in discussion who the individual does not want around them at various stage of their condition and that this can be detailed in their instructions also.
 - include in discussion that some of the areas/sections in The Pocket Advocate may not apply to the individual and this is perfectly fine. That these areas do not have to be completed. Instruct that 'n/a' can be used here.

Equality Monitoring Form

This has allowed us to see if our service has been used by a wide variety of people. The questions asked identified:

- Age group
 - 10% were between the age of 25 to 34
 - 10% were between the age of 35 to 44
 - 50% were between the age of 45 to 54
 - 20% were between the age of 55 to 64
 - 10% were 65 and over

- Whether the participant considered themselves to be 'disabled'
 - 70% considered themselves to be disabled
 - 10% did not consider themselves to be disabled

- Sexual orientation
 - 10% were lesbian /gay
 - 90% were heterosexual

- Ethnic origin (in their own words)
 - 10% Nigerian/British
 - 40% British
 - 10% Irish/British
 - 10% Black British
 - 10% Mixed Race
 - 10% White British
 - 10% Black African

- Religion
 - 30% were Christian
 - 10% were Buddhist
 - 10% were Muslim
 - 30% had no religion
 - 20% were other religion

See attached Equality monitoring Forms

Innovation Indicators

This is how we want to capture your approach and processes. Each of these indicators is derived from research into innovation in the public services and they are scaled to assess key features of an innovative project. It is through these key features that your project can add value in addition to delivering your outcomes. These themes and levels have been developed in collaboration with our innovators. We will use your assessment to build a picture of your project journey.

User involvement and capacity

How has the innovation offered more choice or control to service users: e.g. involvement in decision-making; benefits from new skills or ways of delivering services?

The standard equivalent of The Pocket Advocate is the 'Crisis Card'. Due to their size Crisis Cards tend to be limited in regard to how much information a person can include. The Pocket Advocate is designed in such a way that it is possible for a participant to go into significantly more detail. There are an array of Crisis Cards supplied by various health authorities but nothing that addresses the areas detailed by The Pocket Advocate in the same way

The original design of The Pocket Advocate was inspired by a selection of documents: An Advanced Statement, Care Plan Agreement, Care Plan & Review and a Crisis Card. The main challenges these documents present are that the:

- Emphasis is upon crisis as opposed to earlier stages of an individual's condition
- Awareness of how earlier stages of a condition progress into later stages is not cultivated
- Responsive measures relating to the earlier stages of illness are not detailed
- Bureaucratic presentation of the information contained excludes the user

The Pocket Advocate addresses these issues by including early, intermediate and late stages of a person's condition and presents the information in a way that prioritises the user.

Other potential benefits to the user include being enabled to:

- Bring value to their experience
- Liaise with the individual's medical community to gain insight into their care needs
- Research the details of treatments available in the event of an emergency
- Produce clear instructions to guide themselves and those around them through the different stages of their condition
- Consider what and who feels safe or unsafe when they are unsure of who to reach out to
- Assess the characteristics of the signs they experience at different stages of their condition
- Communicate their needs with clarity and confidence
- Explore their sense of community & who they are able to reach out to for support
- Become respected as an equal voice in the management of their treatment
- Create a stronger partnership with their community and those involved in their care
- Formulate practical strategies to aid their self-management and care as a reminder during the times when they are unsure of how to support themselves

- Prepare for the possibility of hospitalisation
- The process of creating a personalised TPA takes the user through a unique process this empowers the user and often provides for a greater understanding of their experience and diagnosis
- The TPA can be easily revisited and updated
- The TPA also comes as a PDF digital version
- The PDF version can be easily reproduced independently as many times as the user wishes in both an A4 and A3 sized format
- The approach to design is unique and deliberate in its intention to destigmatise mental health conditions
- The approach to design is unique and deliberate in its intention to cater primarily for the user

Please assess a best fit level for your project at this point in time (between 1 and 5)

Level and Evidence: 5

Please explain briefly why you have chosen this level

The Pocket Advocate is truly innovative in respect to its content, design and the way it encourages users, healthcare professionals and a person's wider community to consider and respond to a person's mental health requirements.

Influence and Impact

How is the innovation positively impacting the socially ingrained problem it set out to address? How is it impacting current service provision?

Benefits to the wider community include being enabled to:

- Alert services with more clarity and confidence in respect to the needs of the participant
- Contact other members within the participant's community if in need of support themselves and unsure of what to do
- Gain understanding of the subtle triggers that impact upon the participants mental health
- Gain understanding and recognition of the early/intermediate and late signs that manifest for the participant
- Gain understanding and recognition of the early/intermediate and late intervention, response, treatments and wishes outlined by the participant
- Access the details of treatment requested at various stages of the participant's condition
- Approach the participant with more confidence and enquire into what the participant is experiencing and how they can be of support
- Assess how to support the participant in partnership with the participant
- Contact appropriate support and services according to the participant's needs
- Be given the opportunity, in the form of The Pocket Advocate, to bridge often delicate subjects of discussion regarding the participants mental health and experience
- Create an openness that allows the possibility for a shift in the sense of disempowerment /empowerment, dependent/independent dynamic

Benefits to current service provision include being enabled to:

- Provide a neutral platform that allows a participant and facilitator to discuss areas of the partici-

pants condition that may be otherwise difficult to breach

- This allows an equality between participant and facilitator to arise and in effect return a sense of empowerment to the participant
- Give the facilitator an opportunity to form a more empowered dynamic with their client
- Address the exercises together creates a partnership and bond between the participant and facilitator
- In turn this also supports a shift in the way a participant may approach services overall
- By researching the various resources of support available the participant becomes familiar with those resources which:
 - allows a sense of confidence to arise in respect to taking action
 - broadens the support network of the participant
 - potentially redistributes the pressure placed on facilitating services
- The Pocket Advocate Software encourages the participant and facilitator to focus on the responsibility of the participant in relation to the progression of their symptoms
- The use of The Pocket Advocate during a consultation with their Social Worker/Psychiatrist/GP potentially reduces consultation time as participants can quickly use The Pocket Advocate to refer to where they are in respect to the requirements of their condition
- The Pocket Advocate Online Software is a digital system so it delivers all the related benefits
- The data is displayed in an easy-to-read format bringing obvious benefits over hand written documents
- The data can be exported and utilised in research, patient records and more
- The software is easy to use, provides prompts and guidance
- Organisations using the product can have access to digital records and data retrieval is a rapid process, saving time and money
- Within an agreed period The Pocket Advocate can easily be replaced if lost

Please assess a best fit level for your project at this point in time (between 1 and 5)

Level and Evidence: 5

Please explain briefly why you have chosen this level

The Pocket Advocate is truly innovative in respect to way it positively encourages the individual, their healthcare and personal community to proactively engage with the empowerment of the user and has the potential to shift the, often dependent, disempowering and debilitating social dynamic surrounding the individual.

Organisational culture and capacity for change

How is this project influencing its host organisation? We are interested in capturing how leadership support innovation, how staff and volunteers are involved with it and how the organisational culture is conducive to it.

N/A

Please assess a best fit level for your project at this point in time (between 1 and 5)

Level and Evidence

Please explain briefly why you have chosen this level

Utilising learning

How is the project capturing, using and sharing what they learn from building the innovation.

- Future educational workshops in schools
- Website: raises awareness
- we continue to share what we do with other organisations
- continue to present the work of the project at various forums/community resources and health providers

Please assess a best fit level for your project at this point in time (between 1 and 5)

Level and Evidence: 3

The potential for our organisation to utilise learning is massive. As the majority of our time has been spent developing, trialing and evidencing the service we have not had the opportunity to dedicate as much of our time to this aspect of our journey. We hope that this will be a prominent feature of our organisation.

Please explain briefly why you have chosen this level

Collaboration, partnerships and transparency

How has the innovation facilitated additional collaboration and/or partnership working?

- Volunteer Action Group for Camden. Continue to provide Project Embrace with regular mentoring sessions with particular focus on business planning.
- The Kentish Town Improvement Fund : Managed the funds on behalf of Project Embrace for 2 years.
- The James Wigg Practice : Provided the project with regular mentoring during the first year of development.
- The Kentish Town Health Centre : Provided the project with space from which to operate from. Is currently running a drop in clinic for people with a mental health diagnosis. We hope to work collaboratively with this drop in clinic.
- Camden Voluntary & Third Sector: Provided the project with regular mentoring with a Liaison Officer during the first 2 years of development. We hope to continue to work with other voluntary sector organisations within Camden.
- South Camden Rehabilitation & Recovery Team : Continue to pilot and evaluate the service. This has offered Project Embrace great insight into how The Pocket Advocate functions in the real world. The feedback we have received so far has shaped the refining process of The Pocket Advocate.
- Clean Break: some of their members featured in the short promotional film we made. We hope to present our work to members of Clean Break
- Core Arts : PE will be presenting the work to members
- The Holy Cross: hope to work with their members in delivering the service on some level.

- The Highgate Centre: hope to work with their memers in delivering the service on some level.

Please assess a best fit level for your project at this point in time (between 1 and 5)

Level and Evidence: 4

Please explain briefly why you have chosen this level

This aspect of development is an integral part of our organisation's future. As the majority of our time has been spent developing, trialling and evidencing the service we have not been in the position to dedicate as much of our time to this aspect of our journey.

Sustainability and scaling up

How can the innovative activity be scaled up beyond the funding period and/or long-term sustainability of the project?

Year 1

Main focus

- fundraising
- operation : small
- recruitment
- implementing a strong operational resource & internal systems
- expand operation : small - medium
- evaluation & assesment of service
- qualitive & quantative proof

Independent Participants : Minimum Reach 120 participants : £3,000

Facilitated Participants : Minimum Reach 400 £61,972 - £68,020

Year 2

Main focus

- approach NICE
- endorsement
- fundraising
- expansion of operation : medium to medium - large
- evaluation & assesment of service
- qualitive & quantative proof

Independent Participants : Minimum Reach 500 participants : £ 12,500

Facilitated Participants : Minimum Reach 1,200 participants £95,956 - £ 129,940

Year 3

- Expansion (medium - large to large) & replication of service (small - medium to medium)

Independent Participants : Minimum 2,000 participants : £50,000

Facilitated Participants : Minimum Reach 1,600 participants £ 105,748 - £ 169,972

Please assess a best fit level for your project at this point in time (between 1 and 5)

Level and Evidence: 5

Please explain briefly why you have chosen this level

We are confident that we will be able to sustain develop and grow as an organisation.

