



A positive virtual ecosystem

The theory of change for Kooth

Executive summary

November 2020

Authors:

Dr. Terry Hanley

Programme Director doctorate in counselling psychology, University of Manchester

Aaron Sefi

Research and evaluation Director, Kooth

Janet Grauberg

Organisational strategy & learning consultant

Dr. Lynne Green

Clinical director, Kooth

Dr Julie Prescott

Reader in psychology, University of Bolton

With thanks for invaluable

contributions from the Kooth team:

Aisha Gordon-Hiles

Holly Brick

Anne-Marie Yates

Lex Young

Charlotte Mindel

Kat Cormack

Cherrelle Gayle

Nelly Gentric

We would also like to thank everyone from Kooth who contributed to the coherence check and provided feedback about their work. We hope we have reflected this well.



“ ‘A Positive Virtual Ecosystem - The Theory of Change for Kooth’ is a groundbreaking new piece of research exploring the rich therapeutic journeys of young people through Kooth, the largest digital mental health service in the UK. ”

Foreword

Sir Norman Lamb
Chair, Kooth Advisory Board



We know a lot about mental health today. We have come a long way, especially in terms of stigma, in the last five to ten years. But we also have a great deal still to learn.

We should, for example, understand better the need to provide different ways to ask for and receive support; that there is no ‘one size fits all’. This makes for a complicated picture, but necessarily so.

As we all continue to learn and as I try to apply this knowledge to call for greater investment in services, particularly for children and young people, it’s important to acknowledge the good news stories when they happen. One of these is Kooth.

Kooth is a digital mental health and wellbeing service for children and young people which is really making a difference. Provided via the NHS, it’s an anonymous service available for free in commissioned areas. It’s a thriving online community where young people are discussing self-harm and self-help; where children are having free one to one counselling sessions with trained and experienced therapists and where they are talking to peers about the issues they’re experiencing. Importantly, it is moderated and safe. Kooth calls it a ‘Positive Virtual Ecosystem’ and has been learning from and nurturing this community since 2004.

On Kooth, young people are receiving the mental health and wellbeing education I

wish was available to all of us. To me, and to the tens of thousands of children and young people using the service, it is a light in the dark.

If our son Archie had had access to such a service, as a teenager, when he was feeling alone and trying to cope with OCD, without knowing what was happening to him, I feel sure he would have sought advice there and experienced some preventative relief and an earlier sense of hope.

This report describes the therapeutic journey of children and young people on Kooth. It outlines the different routes they take and defines the most helpful mechanisms for change, which may lead to better outcomes and, ultimately, happier lives. It isn’t a study you’ll find anywhere else. The deep and rich data that Kooth has accumulated over the last 15 years is unique.

It is precisely this knowledge and insight that we need so urgently. It gives us the opportunity to understand better, offer support better and begin to tackle mental health in a way that promises a better, brighter future for so many people.

Introduction

Kooth is an online mental health service for children and young people*. Since its launch in 2004, it has grown with the children and young people who use it, its humanistic approach shaped by their demand and our clinical expertise.

Today it is a large, thriving and diverse community of young people who use it for multifarious reasons and in multifarious ways; importantly, they have the power to direct support themselves. They and are in control of their therapeutic journey. The service is full of choices in terms of how to get help, but also in terms of the therapeutic support available. As such, it is an extremely complex entity, perhaps reflecting the very nature of wellbeing and mental health.

As well as making this an extremely rich environment where young people actively choose to spend their time, it has also taken the service well beyond what today's quantitative outcomes measures of mental health services can capture.

This paper signals the beginning of an important, ground-breaking journey to define the role and the impact of Kooth. We have explored, mapped and categorised activity within the service

with a specific goal in mind: to define our Theory of Change. This describes the Kooth experience and the many routes in and out of the service, each reliant on our understanding of an individual's unique building blocks for wellness.

The Theory of Change (ToC) is not a clinical model and nor does it seek to be. It is not there to show how we can address specific standalone symptoms. Instead it is a characterisation of the broad, person-centred, holistic work Kooth does every day.

It is also the foundation for a future set of mental health outcome measures, which will represent each child or young person's journey.

“ Thank you for listening. its so good to get it out. I literally haven't told anyone about this I can't talk to friends. Im so happy that you could listen it means so much xx ”

~ Young Person on Kooth

“ Talking about stuff is something I never thought I would do. After having a conversation with one of the team I've never felt more understood. I've never felt so free. for once I really hope I'm gonna get better. I really hope so. Thank you ”

~ Young Person on Kooth

Background

The mental health and wellbeing of children and young people receives a great deal of attention from politicians and the press in the UK. The large number of individuals who may benefit from additional support is worryingly high and there have been calls to transform provision. Such calls are perhaps part of a broader 'therapeutic turn' in society, with newer generations shirking some of the stigma that has previously been associated with mental health and wellbeing.

Technology is also bringing change. Digital has huge potential to increase access to support and develop new creative approaches to service delivery.

This potential does, however, come with challenges: we remain in the early days of making sense of the many ways that individuals use online support services; and the development of new technologies makes it incredibly difficult to keep up. Fears that technologically delivered services will be inhuman and mechanistic in nature, or lack the sophistication to respond to the complexity in people's lives, are not unfounded and highlight the need for sustained professional oversight. As such, innovative ways of thinking about such provision are needed.

Digital Natives

Children and young people are 'digital natives'. They have grown up with the Internet and commonly see it as a first point of call when seeking support.

Given the speed of development noted above, it is important for services that offer online therapeutic support to investigate the mechanisms associated with change in

such provision. On Kooth there are many. It has a myriad of access points, both changing and widening the way in which people can gain support for their mental health, shifting the task of supporting young people^[1] to accommodate the need to broaden access to mental health support across the world.

Defining Support

There is a growing need to define what mental health support looks like today so that we have an accurate understanding of the potential of new approaches and new modes of delivery. It also follows that we need to evolve our understanding of outcome measures so that we avoid using old systems to measure newer, broader services. The ambition of this

project, therefore, was to articulate and share the Theory of Change for the Kooth platform, an online service based upon the humanistic psychology principles - i.e. one that believes that individuals are unique, have the capacity to grow constructively and make informed choices given the right environment. Future work will address the outcomes required to evidence this work.

Method

A qualitative action research design was adopted in this project. Kooth practitioners worked collaboratively with the research team to develop a detailed understanding of how young people engage with the different elements of the service on offer.

A total of 14 Kooth staff (two researchers, two content developers, two product managers, five practitioners, and support from three senior staff) completed a series of practitioner-research projects focusing on the different ways that individuals use Kooth. These projects investigated how young people engage with the platform and examined what might be viewed as successful outcomes. The practitioner-researchers used real world information and explored this systematically using thematic analysis. They generated thematic maps illustrating the different pathways through Kooth.

These projects informed the development of an overarching ToC for Kooth. In addition, as the understanding of the service delivery developed, a series of ToCs were developed concurrently that focused on auxiliary support systems (SuS) on offer on the platform (static content, peer support and professional support).

Drafts of the ToCs were shared with 30 practitioners, eight managers and senior practitioners and seven service users, each asked to review them for coherence. The feedback from this consultation exercise was discussed with the research team and amalgamated into the final ToCs.

Findings

The work highlighted the importance of considering the service as a whole, rather than as a series of components. As such, the broader ‘virtual ecosystem’ was prized as a dynamic resource in which young people could take ownership of their support pathways if desired. Kooth is proactively moderated so that individuals can feel safe and valued, successfully mitigating the impact of many negative online environments. It is viewed therefore

Positive Virtual Ecosystem (+VE)

- Caring and Supportive
- Non-Judgemental
- Safe and Confidential
(Anonymous where appropriate)

Support Systems (SuS)

1. Static Content
2. Peer Support
3. Professional Support

Domains:

- SuS 1:** Therapeutic Content and Peer Support
- SuS 2:** Therapeutic Content and Peer Support
- SuS 3:** Reactive/Responsive Therapeutic Support
- SuS 3:** Structured Therapy
- SuS 3:** Ongoing Therapeutic Support

as a ‘Positive Virtual Ecosystem’ (+VE). Figure 1 provides a visual overview of how the different support systems and pathways of support on offer might interact and overlap for young service users.

A ToC for the Kooth service was arrived at that helps to understand how this way of working can support positive change (see Figure 2 on the next page). As is evident within the ToC formulation:

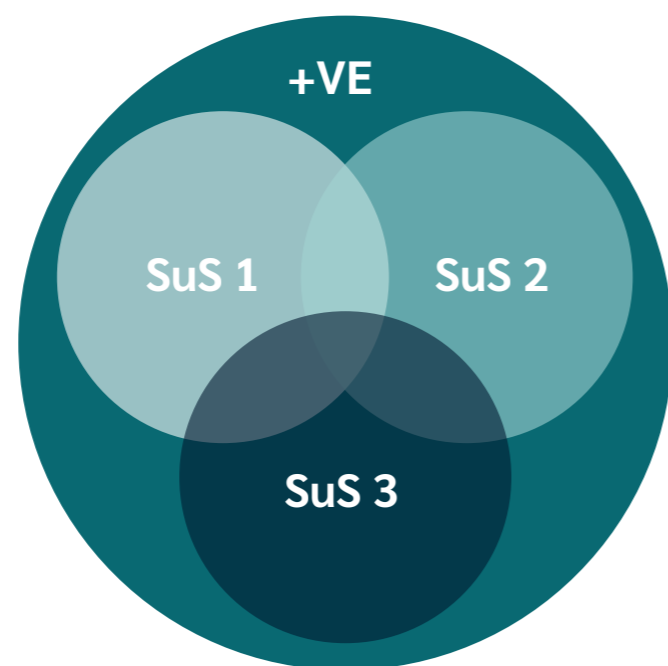


Fig 1: The Positive Virtual Ecosystem (+VE) offered by Kooth

Description	CYP Characteristics	Service Inputs	Worker Activities	CYP Activities	Outputs	Desired Outcomes	Impact
	<p>Want support there and then/ quickly Don't have/ want family & friends to turn – may be in a marginalised group</p> <p>Curious, exploring, or looking for information and reassurance Unable or unwilling to access face to face services</p> <p>Comfortable with or even a preference for online communication</p> <p>Seeking a non-judgemental space online</p> <p>Seeking a different connection with others</p>	Triage/Decision to offer a service	<p>Skilled and experienced professionals</p> <p>Flexible access platform available out of hours, and written information/ articles available 24/7.</p> <p>Robust clinical governance & risk managed through clinical oversight</p>	<p>Building an empathetic relationship</p> <p>Drawing on professional understanding of child and adolescent development</p> <p>Assessing distress and risk and tailoring responses</p> <p>Giving information and signposting</p> <p>Co-creating goals and solutions with young people</p> <p>Identifying what has helped before</p> <p>Encouraging reflection & taking responsibility</p> <p>Exploring the young person's relationships and support systems</p>	<p>Offloading their worries</p> <p>Opening up, articulating, and sharing their story</p> <p>Learning about mental health so they can understand their experiences</p> <p>Exploring their thoughts and feelings</p> <p>Building a trusting connection with the worker</p> <p>Identifying coping skills and testing out approaches</p>	<p>Feels heard & has feelings validated</p> <p>Gets information</p> <p>Changes perspective/ sees new options</p> <p>Has experienced opening up to someone & built a relationship with a professional</p> <p>Takes ownership of an issue</p> <p>Starts to engage/ has information about face-to-face services</p> <p>Builds connections and a safe online and offline community</p>	<p>Safer/ crisis reduced</p> <p>Able to reflect on thoughts, feelings and perceptions</p> <p>Able to consider future strategies</p> <p>Able to engage with other services</p> <p>Greater self-awareness and emotional regulation</p> <p>Acknowledges a reduction in stress</p> <p>Achieves personal goals and recognises progress made</p> <p>Feels a sense of community</p>
Conditions	Delivery			Change			
Linking Assumptions	Who can benefit?	Service Attributes	Mechanisms of change - generic				
	<p>Can go at own pace Particular needs for accessibility – time/remote/ ease of access/ lack of stigma</p> <p>May not want parents or outside professionals involved</p> <p>Want a service they can dip in and out of as needed</p>	<p>Immediate/ quick response</p> <p>Offering a range from prevention to specialist support without thresholds</p> <p>Informed by NICE recommendations and evaluated models</p> <p>Offering a range of therapeutic approaches</p> <p>Integrated with partner local services</p> <p>Linked data means workers see previous history</p> <p>Designed to be both user-friendly and manage data securely</p> <p>Perceived by young people to be both youth friendly AND safe</p>	<p>Young person has a safe space to reflect on their thoughts & feelings. This enables the young person to gain reassurance; identify coping mechanisms and take on information about next steps</p> <p>Mechanisms of change - specific to Kooth</p> <p>Kooth offers young people time to be heard, without being pushed or challenged to make changes until they are ready.</p> <p>Its accessibility means that young people can use it when they need it, and go back for more as they feel they need to. The young person is control of the pace of the intervention – this shifts the power dynamic.</p> <p>Anonymity means the young person feels it is safe to open up to the worker and can get to the key issues more quickly.</p> <p>Typing words and sentences means the young person has to process their feelings in their head rather than talking - what they've said about themselves appears more starkly than if they were talking and the words were gone after they'd said them</p> <p>The absence of a face-to-face relationship means that the young person does not need to attend to the worker. This lessens the fear of judgement or dismissal. This creates a space for the young person to think differently or play out different roles.</p> <p>The young person has an opportunity to build trust with a worker on their terms, so they are more likely to engage with suggested actions. This may be a gateway to engagement with other mental health services.</p> <p>The worker's mindset is that they have to deliver there and then as mostly they don't know if the young person will return.</p> <p>By going through a positive experience of being helped and learning about what works, the young person is more likely to want to use these skills to help others and see this as a therapeutic experience.</p> <p>The combination of an anonymous, flexible and multi-offer space means that the young person builds a therapeutic alliance with Kooth, rather than an individual practitioner.</p>				
Conditions	Delivery	Change					

Fig 2: The Kooth Theory of Change

? Understanding the Kooth Theory of change

By providing accessible support in an online platform, Kooth has a unique way of contributing to change in a meaningful way for young people.

For example - one mechanism of change - 'the absence of a face-to-face relationship means the young person does not need to attend to the worker' can have a profound effect on the way young people can see themselves reflected back in their work on Kooth - and begin to take responsibility for change.

Another key aspect is the way they perceive Kooth to be both youth-friendly AND safe. A safe space online as defined by the Positive Virtual Ecology principle (+VE) but also accessible - through anonymity, and different support channels offering choice and flexibility.

In addition to the development of a whole service ToC, four pathways were noted and agreed on. These categorised the different ways that young people have been using the Kooth service. These are outlined in Figure 3.

These pathways reflect the many ways young people use the different support systems on offer (static content, peer support and professional support). The first combines two support systems that involve limited direct contact with practitioners. The others reflect the variety of ways young people are engaging directly with professionals on the Kooth platform.

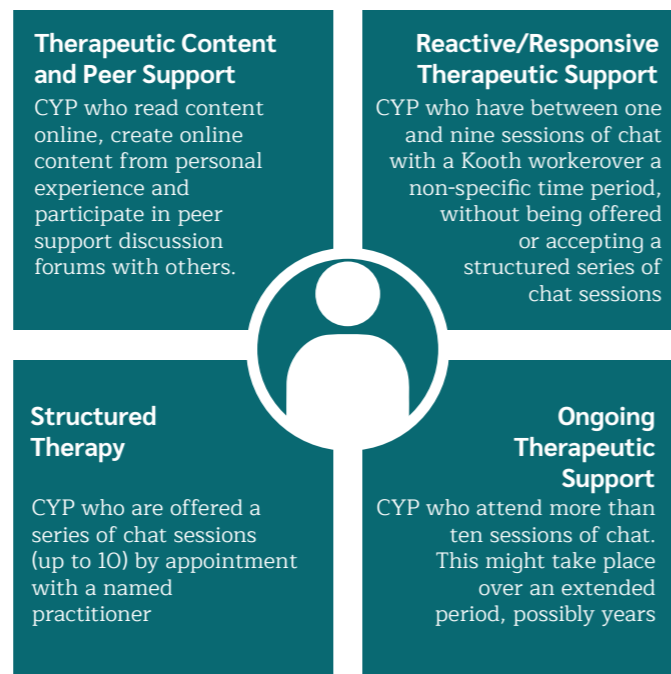


Fig 3: Pathways

? An insight into Kooth pathways

These pathways are important distinctions to understand the different ways in which young people can use the service. Whilst separately defined here, young people can move through them depending on need and clinical appropriateness.

The large majority of young people who graduate to professional support use the 'reactive' pathway, preferring to access support as and when suits them, and in a way that works best for them. This dynamic encourages a 'solution focussed' mindset in the practitioner - to manage the issue there and then, and find solutions, or

offer information for further consideration. This in turn can signpost them to content and peer support provision within the service for follow up.

The structured and ongoing pathways of professional support are used by a much smaller proportion of young people, but by nature use higher amounts of service time and resource, reflecting the nature of their more involved mental health issues. These young people can and do use peer support and content as additional support, as described in the +VE, creating a support structure in Kooth.

These pathways reflect the many ways young people use the different support systems on offer (static content, peer support and professional support). The first combines two support systems that involve limited direct contact with practitioners. The others reflect the variety of ways young people are engaging directly with professionals on the Kooth platform.

As stated, a separate ToC has been produced for each of these pathways noted above. These are not presented in this executive summary, but are available in the longer version of this report. These pathways are not always

strictly followed, and nor should they be. Many individuals, for example, might find themselves moving in and out of a number of the pathways. This can be challenging when trying to measure and define the service, but equally, this flexibility is considered a major asset to young people. With many services, young people might feel overly influenced and directed by professionals. Young people using online support services, however, are able to direct the support they receive. This does not come without challenges but it opens up a channel of support for some young people who would not ordinarily consider using a support service.

The ToCs that have been developed highlight the complexity inherent in trying to develop a measurement tool that is sensitive to the wide variety of outcomes that might be present in online mental health and wellbeing support services. With this complexity, and a movement away from focussing on reduction in symptoms, it is important to consider what exactly young people are looking for from an

open access service such as Kooth. A high-level understanding is therefore suggested as a means of looking at how change might be considered. From the analysis of the ToC findings, a simple outcome matrix emerged that combines (i) the way that service users may look for informational or emotional support, with (ii) consideration of the way that the support impacts on themselves or their relationships with others:

	Emotional Support	Informational Support
Intrapersonal	e.g. “I understand myself more”	e.g. “I can identify with something important to me”
Intrapersonal	e.g. “It helps me relate to others”	e.g. “I have some skills I want to try with others”

This simple frame can be utilised as a starting point to stratify each individual’s wants and needs from the platform. It can also be used to gauge whether the support was judged by the individual to be effective. Such a matrix can provide a basis for developing a new set of outcome measures that are fit for purpose for digital therapeutic support.

Conclusions

Through sustained exploration, we have articulated the Kooth experience via a Theory of Change. It has helped to gain a greater understanding of some of the complexities that are inherent in the provision of online mental health and wellbeing provision. Specifically, it:

- Provides an important insight into the way that services, such as Kooth, attempt to create a Positive Virtual Ecosystem (+VE), a safe and trusted way of accessing support online. Services taking this approach are important at a time when regulation of the Internet is limited
- Highlights the wide variety of ways that young people tailor and direct the support they receive through the Kooth platform. This has great potential but needs to be considered cautiously. Collaboratively developed care pathways need to sensitively manage the interface between professional skills and their choice
- It reminds us of the need to avoid one-size-fits-all approaches of support with young people. Individuals might tailor

their support to include professionals or not. Support can vary in length from minutes to years and may be responsive to individuals with immediate needs, or tightly structured in advance

- Demonstrates the complexity of attempting to capture outcomes in an anonymous online support service for young people. The ToCs developed for the different pathways of support reflect the many reasons that people access support. It is therefore suggested that a high-level consideration of the wants and needs of young people should be considered as a starting point for assessing outcomes. This should capture whether individuals believe they have received informational or emotional support from the +VE that has impacted their understanding of themselves or others.

Developing both the overarching and pathway-specific ToCs for the Kooth service is an important step in understanding the work of such Positive Virtual Ecosystems. They do however, almost inevitably, raise as many questions as answers. It will be important to:

- (i) Regularly revisit and reflect on the utility of the ToC with a view to accommodating the dynamic nature of online technologies
- (ii) Delve deeper into the different pathways to gain a greater understanding of how best to serve the young people using the services
- (iii) Work to develop ways of capturing outcomes in each of the pathways that are integrated, rather than intrusive, within the services being provided.

Key Contributors



Aaron Sefi

Aaron is the Research & Evaluation Director at Kooth - an academic with substantial experience in counselling and Mental Health Research.

Dr. Terry Hanley

Dr. Hanley is a Senior Lecturer at the University of Manchester, a renowned expert in the study of psychology and advisor to masters and doctorate programmes.



With special thanks to:



Dr. Lynne Green
Kooth



Janet Grauberg
Consultant



Dr. Julie Prescott
University of Bolton

...and the brilliant Kooth team

Aisha Gordon-Hiles | Anne-Marie Yates | Charlotte Mindel
Cherelle Gayle | Holly Brick | Lex Young
Kat Cormack | Nelly Gentric



To read our full report, visit explore.kooth.com/toc

