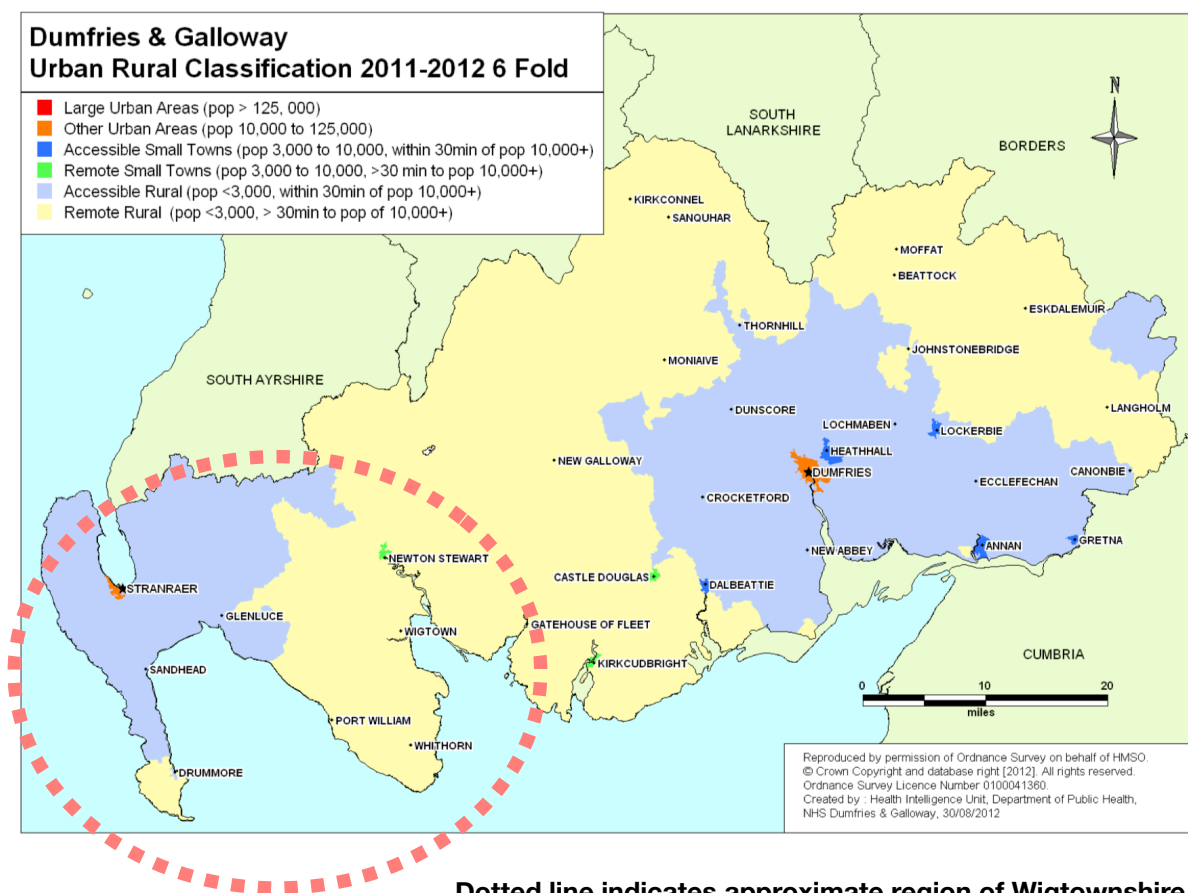# Aeriel: Online

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Aeriel Music Therapy (Aeriel) is a non-profit organisation dedicated to offering music therapy to people with diverse complex needs, such as traumatic brain injury, learning difficulties, dementia and mental illness in South West Scotland. This report asks two main questions:

1. How might music therapy enable further participation in community activities for adults living with complex needs across Wigtownshire?

2. How does an online forum work as a resource for engagement with music therapy across a remote rural population?

Aims and Purpose

This project explored the scope and range of music therapy need across Wigtownshire, an area of remote rural South West Scotland, and in doing so appraised online community platforms as a research site. It investigated the functionality, appeal and mechanisms of specifically-designed social media interfaces in music therapy research. Aeriel is based in a remote part of Dumfries and Galloway. Nearly half of all people in Dumfries & Galloway (46.9%) live in areas classified as rural, which is defined as living in settlements with fewer than 3,000 people. The only urban areas are the towns of Dumfries and Stranraer, though neither of these is classified as a large urban area. In terms of accessibility, nearly a third (30.3%) of the population live in areas classified as remote, which is defined as further than 30 minutes drive away from a large town.

Dotted line indicates approximate region of Wigtownshire

According to the most recent report on the population and its health in Dumfries and Galloway[1], sixteen areas of Dumfries and Galloway are in the 20% most deprived in Scotland. Aeriel's local area is one of those. This signals that access to health services, information and opportunity are significantly restricted, leading to the likely outcomes of poor health and low social access. However, one method of widespread social connection is online, specifically via facebook. Most social connection and messaging takes place via this platform, even on statutory health matters such as GP opening times or new health initiatives in the region. While Facebook is core to messaging around arts, health and care in the region, it is notoriously insecure around data, and would not present a viable site of research. This project used www.blognog.com, an alternative data-secure online community to establish the pros and cons of using it for further research. It ran from August to October, 2019.

Project Description

The project led with two main questions:

1. How might music therapy enable further participation in community activities for adults living with complex needs across Wigtownshire?

2. How does an online forum work as a resource for engagement with music therapy across a remote rural population?

This opened exploration both to logistics of music therapy service delivery in the region, and also to feasibility of online engagement as a research method.

Literature

The field of netography is a valuable framework for addressing the fast-changing study of digital communities and online engagement. It is a form of ethnographic research adapted to include the use of the internet (Ivan, 2019). This field offers a framework for understanding sites such as BlogNog as a tool for research amongst health and social care professionals. Qualitative research also exists that points to online communities as a viable research platform for exploring the needs and assets of potential users of leisure services (Vidiasova & Grigoryeva, 2018). There is also evidence that online research has been used to determine the potential for distance learning and other forms of input across remote communities or hard to reach populations (Ramachandran, 2018). This project addressed a gap in interdisciplinary collaboration around service delivery, and also a gap in the literature around how online research communities might inform the development of music therapy services.

Aeriel: online created a data secure online forum via www.blognog.com, a qualitative research platform with the look and feel of an online community such as Facebook. Blognog is free for small user-groups within a research context. Screenshots of the platform are included below. Invited participants were representatives of health, social care and education agencies in the region, such as the local representative of Alzheimer Scotland, the Manager of the local adult education resource, family members accessed via convenience sampling and allied health

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[1] Dumfries and Galloway: The Population and its Health, Health Intelligence Unit, Department of Public Health, January 2014.

professionals working in statutory posts across Dumfries and Galloway who have expressed an interest in generating network knowledge about music therapy. Through a range of semi-structured discussion questions and prompts, the research generated discussion around the needs, assets, resources and interests of service users in the region. A thematic discourse analysis was be applied to the content discussions after a period of open engagement, and a data narrative was constructed from the statistics on participation that are provided by the site.

Participants

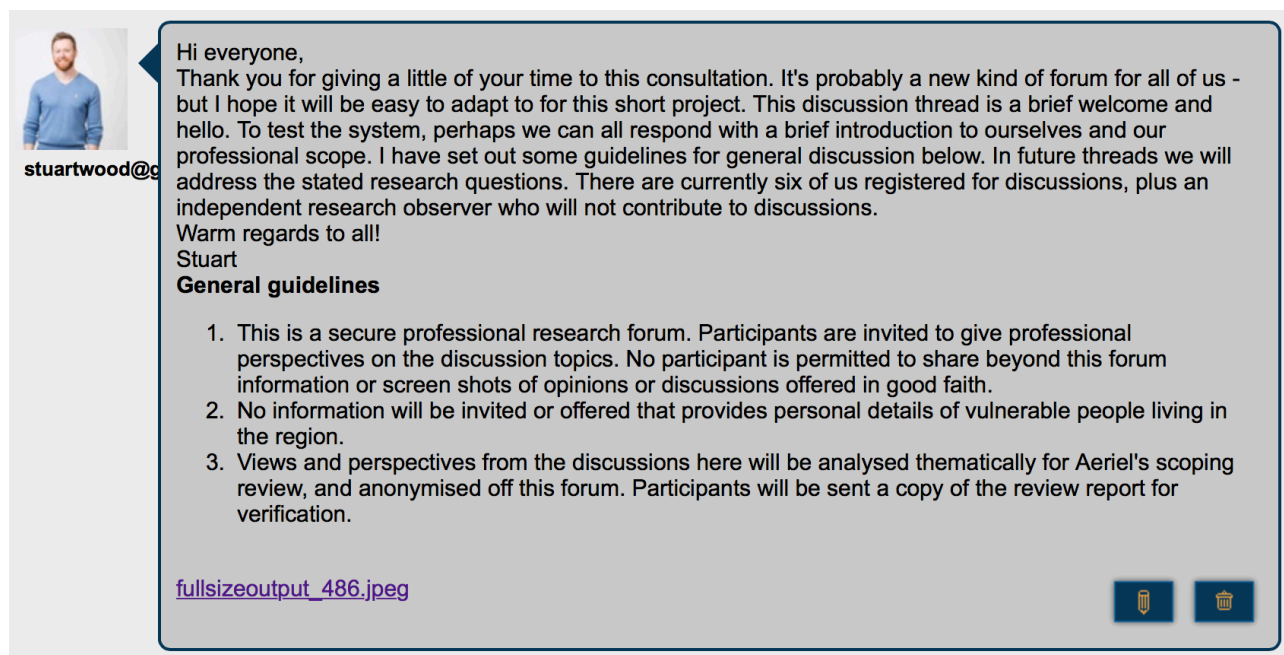| Professional Role / Sector	Confirmed	Log-in
Aeriel, Director	Y Moderator	Y
Aeriel, Director	Y Observer	Y
Wigtownshire Stuff	Y 1597participant1	Y
Activity and Resource Centre	Y 1597participant2	N
User and Carer Involvement Network	Y 1597participant3	Y
NHS D&G Building Healthy Communities	Y 1597participant4	N
Compass Brain Injury	Y 1597participant5	Y

Protocol

One week per discussion topic was allocated. The topic plan was as follows:

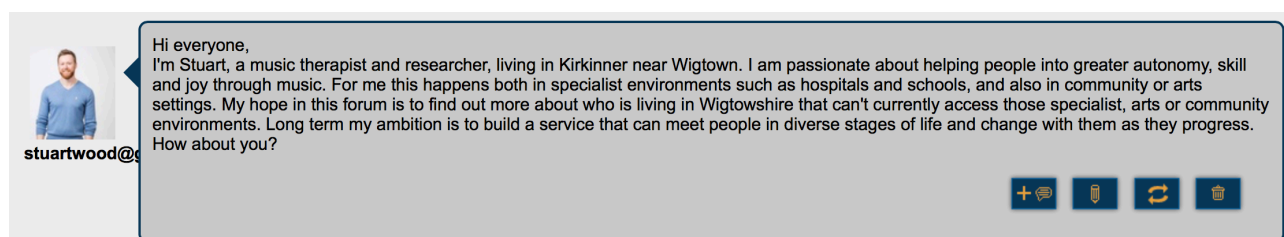| Week	Topic	Guide Question
1	Welcome & Introductions	
2	Service users: demographics / profile	"It's believed that there are adults in Wigtownshire living with learning difficulties, head injury or other complex nursing needs who can not currently access services. What's your view on this?"
3	Obstacles to participation	"What are the main reasons that people don't access the services available?"
4	What do we need from a MT service?	"How would a MT service have to work, if it were to make meaningful connections with hard to reach people?"

Look and Feel of BlogNog

Below are screen shots of the online research forum. They show how it appeared to informants, and the register of voice that the study aimed to maintain.

Hi everyone,
Thank you for giving a little of your time to this consultation. It's probably a new kind of forum for all of us - but I hope it will be easy to adapt to for this short project. This discussion thread is a brief welcome and hello. To test the system, perhaps we can all respond with a brief introduction to ourselves and our professional scope. I have set out some guidelines for general discussion below. In future threads we will address the stated research questions. There are currently six of us registered for discussions, plus an independent research observer who will not contribute to discussions.
Warm regards to all!
Stuart
General guidelines

1. This is a secure professional research forum. Participants are invited to give professional perspectives on the discussion topics. No participant is permitted to share beyond this forum information or screen shots of opinions or discussions offered in good faith.
2. No information will be invited or offered that provides personal details of vulnerable people living in the region.
3. Views and perspectives from the discussions here will be analysed thematically for Aeriel's scoping review, and anonymised off this forum. Participants will be sent a copy of the review report for verification.
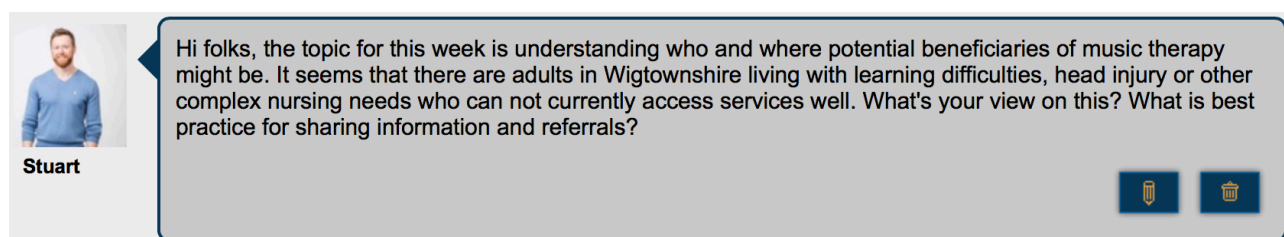
fullsizeoutput_486.jpeg

Welcome & Introductions

Each informant could use their own choice of image - either a cartoon avatar from the site's stock, or by uploading a photograph. All informants used a cartoon avatar, apart from the report author.

Hi everyone,
I'm Stuart, a music therapist and researcher, living in Kirkinner near Wigtown. I am passionate about helping people into greater autonomy, skill and joy through music. For me this happens both in specialist environments such as hospitals and schools, and also in community or arts settings. My hope in this forum is to find out more about who is living in Wigtownshire that can't currently access those specialist, arts or community environments. Long term my ambition is to build a service that can meet people in diverse stages of life and change with them as they progress. How about you?

Example prompt

Each week I uploaded a new prompt for informants to respond to. We also encouraged clarifications or tangents when they arose. This was easy to follow using the forum's interface.

Hi folks, the topic for this week is understanding who and where potential beneficiaries of music therapy might be. It seems that there are adults in Wigtownshire living with learning difficulties, head injury or other complex nursing needs who can not currently access services well. What's your view on this? What is best practice for sharing information and referrals?

In-person Focus Group

It was agreed amongst all participants that the online forum only took the discussion to a surface level of information. This was due to the time limits available for accessing, thinking, and contributing; but also to the lack of interpersonal energy and provocation that is typical of online chat methods. Informants speculated whether it was also a symptom of everyone being a 'people person' and perhaps with other users or professionals from other sectors, this might not apply. In any case, the invitation to meet in-person was met with enthusiasm.

A half day was hosted by the staff at the Activity and Resource Centre in Newton Stewart, catered from the research study funds. The protocol was expressly free ranging and unstructured, lasting two hours. The conversation was transcribed and analysed using the same open coding method as applied to the written text of the online forum. Data have been synthesised in the summary below.

Data Summary

Who is out there?

All informants agreed that there are individuals who cannot access services well currently. Indeed, some don't access services at all, as some individuals won't be known to health, social care or education services. It was suggested that it appears from various studies that only a minority of people with a Learning Difficulty for example are known to services. It is also reported that as eligibility for services is getting tighter, many potential users in Wigtownshire will be living with their needs unmet, in rural or even remote areas without access to transport. Hidden disability can make eligibility, communication and organisation harder. However, informants were in agreement that the traditional criteria for judging eligibility for statutory services do not necessarily need to apply to an Aeriel music therapy service: "it doesn't matter whether you've one diagnosis or another or none…"

What are the current obstacles to reaching people?

Many potential beneficiaries of a music therapy service will currently be hindered by one or many of the following obstacles:

- Lack of motivation/understanding from support staff
- Possibly no support
- No confidence to attend events
- Stigma
- Time and timing of groups
- Stereotypes and associations with specific user groups
- Neurodiversity, eg hypersensitivity
- Poor access to information, to physical buildings, to social interactions
- Isolation, rurality
- Lack of formal diagnosis
- Lack of history with health services

Recommendations for a new service

In summary, informants felt that a useful and forward-thinking Music Therapy service for users with complex needs in Wigtownshire should be:

Mobile: with funding for practitioner travel and/or a mobile music unit

It was agreed that the service should be as decentralised and mobile as possible: "*in buildings we are not good at people who challenge the system…there are people who are not coming to buildings…*"

Flexible with planning

It was felt that the service should make the most of its unstatutory roots, and its creative modality, "*being so approachable that you can say or do anything…understanding role…not just trying to please all the time…not putting up barriers…*"

Varied in session formats

Informants were highly energised by the scope of a music therapy service to be imaginative and varied in what it offers users: "*…there is also a view that 'groups are good' - why? Each individual is unique. Going in a group might be way too much for some people. That person might benefit from just one or two people.*"

This however was not only in the direction of cultural activity, but also towards offering safe, reflective spaces: "*Everybody needs down time…have some inward time…rather than going and doing all the time.*"

It was also felt to be important that there were clear indications of what was possible or appropriate for each type of format: "*…somebody might just want a session of music, and be coming for that. Some might come for 'therapy', so if there is a choice for them, they are separate things…*"

Connected to, but not part of, statutory services (inc training and updates)

Aeriel's status as a CIC was universally felt to be an advantage, but only if it maintains trusting communications with existing statutory services: "*Some individuals will therefore be just getting by as best they can and not known to Social Work. However, they may well be known in some capacity to health services. Part of the answer in letting folks know about any music therapy is through communicating in variety of ways to health professionals.*" Establishing healthy professional relationships with all key figures in the statutory landscape was seen as a clear imperative: "*…we need to go through gate keepers.*"

Connected to social and cultural life of community

Alongside the need to keep good professional contacts, it was also important to informants that Aeriel is part of the wider cultural landscape, and takes advantage of its position to be creative:

"…maybe Aeriel should be thinking more about what would people love to do that can't be done between 10-3 in the day, or isn't yet possible within current structures - for example the Gig Buddy idea…"

"That's the massive untapped…we're still seeing that deficit model. People are not getting out to places such as the cinema…you want the person helping to be enjoying it too…"

It was felt that Aeriel could spearhead a "different approach to using the resources of the town outside tourist season, for example hotels offering tea events for older people when their own services are closed."

Organised / communicated via direct personal contacts and diverse types of networks

In line with the ethical principles of all the contributing groups, it was agreed that Aeriel also should be run in a personal, and personalised way: *"Social media is a crucial way to communicate"*

" any partnership has to involve the folks themselves and the families themselves…"

This led to the novel idea of creating a matching service for carers or peers to act as a 'gig buddy' for other supported people, perhaps creating a *"'care tinder' to find the right person to be a gig buddy".*

Informed on ongoing basis by health, social care and education stakeholders

Finally, informants offered several very useful suggestions as to how Aeriel can become more informed, making its data gathering methods more user-friendly and engaging: *"make people think about the options connected to what you do…that's when people are allowed to think it's OK to get what they want from it"*

"Sometimes I want people to say 'actually that was crap'. There are dangers in letting carers and family speak for users."

Recommendations for Research

It became apparent that the use of a secure online chat forum had limits. Blognog for example has too many clicks to allow for quick and easy contribution. The informants had to set aside designated times to access and respond to the project, which could have equally been used in a phone call or email thread. As time is limited for all informants, it was felt that an additional half-day focus group both allowed for a valuable time-out, and enabled more quality reflection. All users agreed that an in-person discussion was still the best way to generate new knowledge and to establish rapport. Further, it was felt that despite its security risks, Facebook would attract more varied user informants and create a less hierarchical dynamic. A future scoping study would make more integrated use of online and in-person data methods. This project has however contributed invaluable data to a further funding bid to expand the service and refine its own data gathering methods, advancing the work of music therapy in the region on a more informed basis.

References

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Ramachandran, V. (2018). "A framework for making most out of online communities of practice tools for reforms in distance learning." *Asian Journal of Distance Learning.* 13(1), 146-156.

Vidiasova, L & Grigoryeva, I. (2018). "Investigation of internet-communities' influence on the social inclusion of the elderly people through leisure practices." *Advances in Gerontology*, 31(4):597-603.