An evaluation of the impact of the online Community of Practice, “Working in the community with children with cerebral palsy”

What is the role of a global Community of Practice in supporting the training of health care practitioners? Lessons learnt from a community disability training programme.

Date: July 2019

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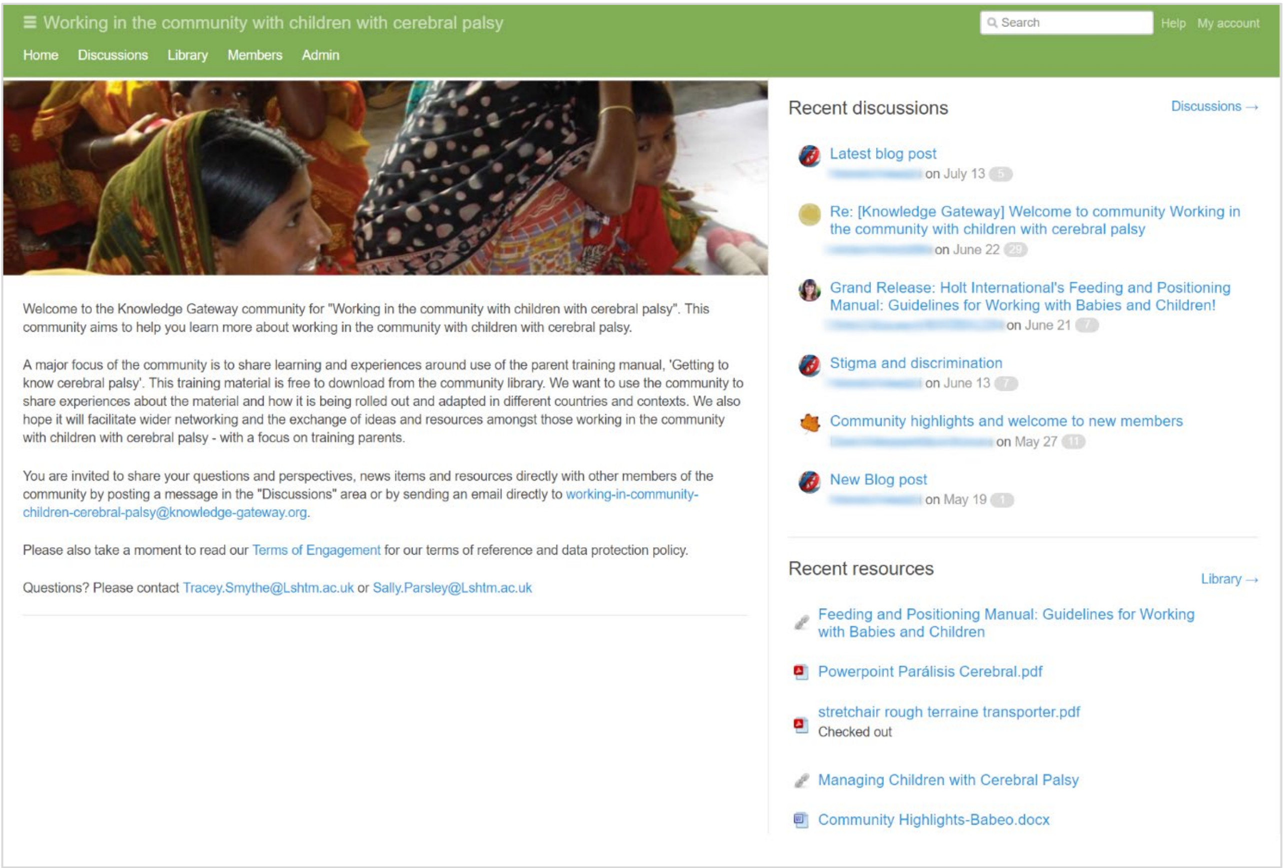

Welcome to the Knowledge Gateway community for "Working in the community with children with cerebral palsy". This community aims to help you learn more about working in the community with children with cerebral palsy.

A major focus of the community is to share learning and experiences around use of the parent training manual, 'Getting to know cerebral palsy'. This training material is free to download from the community library. We want to use the community to share experiences about the material and how it is being rolled out and adapted in different countries and contexts. We also hope it will facilitate wider networking and the exchange of ideas and resources amongst those working in the community with children with cerebral palsy - with a focus on training parents.

You are invited to share your questions and perspectives, news items and resources directly with other members of the community by posting a message in the "Discussions" area or by sending an email directly to working-in-community-children-cerebral-palsy@knowledge-gateway.org.

Please also take a moment to read our Terms of Engagement for our terms of reference and data protection policy.

Questions? Please contact Tracey.Smythe@Lshtm.ac.uk or Sally.Parsley@Lshtm.ac.uk

Recent discussions

Discussions →

Latest blog post
[redacted] on July 13 5

Re: [Knowledge Gateway] Welcome to community Working in the community with children with cerebral palsy
[redacted] on June 22 29

Grand Release: Holt International's Feeding and Positioning Manual: Guidelines for Working with Babies and Children!
[redacted] on June 21 7

Stigma and discrimination
[redacted] on June 13 7

Community highlights and welcome to new members
[redacted] on May 27 11

New Blog post
[redacted] on May 19 1

Recent resources

Library →

Feeding and Positioning Manual: Guidelines for Working with Babies and Children

Powerpoint Parálisis Cerebral.pdf

stretchair rough terraine transporter.pdf
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Managing Children with Cerebral Palsy

Community Highlights-Babeo.docx

Front page of the CoP on the Knowledge Gateway platform

Acknowledgements

There are so many people to thank in the development, contribution to, and evaluation of this Community of Practice. It has been a learning journey for all of us. We would like to say a particular thank you to the advisory committee for the CoP and to our disability champions. And a thank you to all of those members who have engaged with the CoP and the evaluation in one form or another.

Thank you to CBM International for the funding of the Community of Practice.

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Executive Summary

The CoP can be used to find ways to bring expertise and resources together, it allows the little man with lots of lived experience to access scientific research, knowledge and to share their own. Its strength is in offering a space to share diverse opinions in a non- confrontational way.

- An on-line Community of Practice (CoP) was established in spring 2014 to support the roll out of a training programme for caregivers entitled "Getting to know cerebral palsy" (GTKCP). The overall aim was to support the use of accompanying parent training manual developed by the project (the GTKCP manual), and also to encourage good practice generally in community-based work with children with cerebral palsy.
- Currently the CoP has 412 members spread across 72 countries. This consists of parents, practitioners and academics.
- This was a mixed methods evaluation. It included a baseline and end-line survey, in-depth interviews, a membership analysis, and a thematic content analysis of messages posted over a 16-month period.
- Two years after the launch of the CoP there were 233 members from 57 countries and 54% of the membership were from low and middle-income countries.
- Most contributions were sharing knowledge and resources. Discussions about the training manual were a catalyst to a wider range of discussions and wider resource sharing. Approximately half of the postings related to the manual and half about more general working with children with cerebral palsy and other neurodevelopmental conditions.
- 51% felt that the CoP had helped them increase their skills, 44% that it had challenged some of their attitudes and 42% that it had helped them expand their knowledge.
- A key theme of the evaluation was the value placed on sharing encouragement and reassurance in how to use the manual. Summarised here by one interviewee: *"It has really improved my own knowledge, because I now know this lady in in South Africa …and meeting such people [on-line] has made me feel that I'm on the right track"*
- Finding out what others are doing and what is possible was seen to be a key benefit of the CoP, particularly when members first began to use the manual. Practically, it was helpful to connect with people in the same country, and to also find out if local translations of the material were available. This networking also led to collaborations on translations in a variety of languages.
- In terms of improved delivery of the manual, 46% agreed/strongly agreed that they had made changes to their working practice using knowledge gained from the CoP. 20% had used the GTKCP manual for running parent groups, as intended. Interestingly, 62% had used the manual for general training of staff and community volunteers.
- The human networking element of the CoP was highlighted as the most important benefit of the CoP. Aside from global networking, it frequently resulted in finding people to contact from within a country, which then often opened up other avenues of support.
- Social knowledge-building, that is problem-solving and co-creation of knowledge through interactions, was less evident in the CoP discussions. There was some evidence that some more in-depth discussions were taken off-line.
- A key enabling factor appeared to be the very supportive environment for the community.
- Although only a small percentage of members frequently posted, it was evident from the interviews and survey that other members were content to learn through being passive members: "*I have been reading more than contributing to this forum enjoying and benefiting from the rich experience this forum brings."*

Introduction

What is a Community of Practice?

Communities of practice (CoPs) are groups of people who interact regularly – in 'real' life or virtually - on a shared topic of interest [1]. CoPs recognise that knowledge is both social and constructed, supporting collaborative and practical learning through interactions in settings close to members' actual practice [2], [3]. The potential of CoPs to share and increase knowledge in the health care sector has been recognised [4] and a 2011 literature review found indications that they can have a role in improving healthcare performance [5].

Background to the CoP "Working in the community with children with cerebral palsy"

The International Centre for Evidence in Disability (ICED) launched a new on-line Community of Practice in the spring of 2014, to coincide with the launch of a new training material called 'Getting to know cerebral palsy' (GTKCP). This was supported by funding from CBM International. This was a participatory caregiver training package for children with cerebral palsy. The idea was to use the CoP to promote the sharing of experiences around the implementation of the GTKCP, and, more generally, around working in the community with children with cerebral palsy. The CoP aimed to support teachers, CBR workers, parents, therapists, and anybody who works with children with cerebral palsy and their families in the community. The overall aim and objectives were:

Aim:

1. To support the adoption and use of the GTKCP manual by practitioners who are working in the community with children with cerebral palsy

Objectives:

1. To improve knowledge and practice around the GTKCP manual, and more generally, working in the community with children with cerebral palsy
2. To connect with peers, experts and technical advisors, explore partnerships and build alliances to enhance coordination and synergies between individuals and organisations
3. To exchange ideas and new materials with other members to learn and innovate.

The CoP platform and process

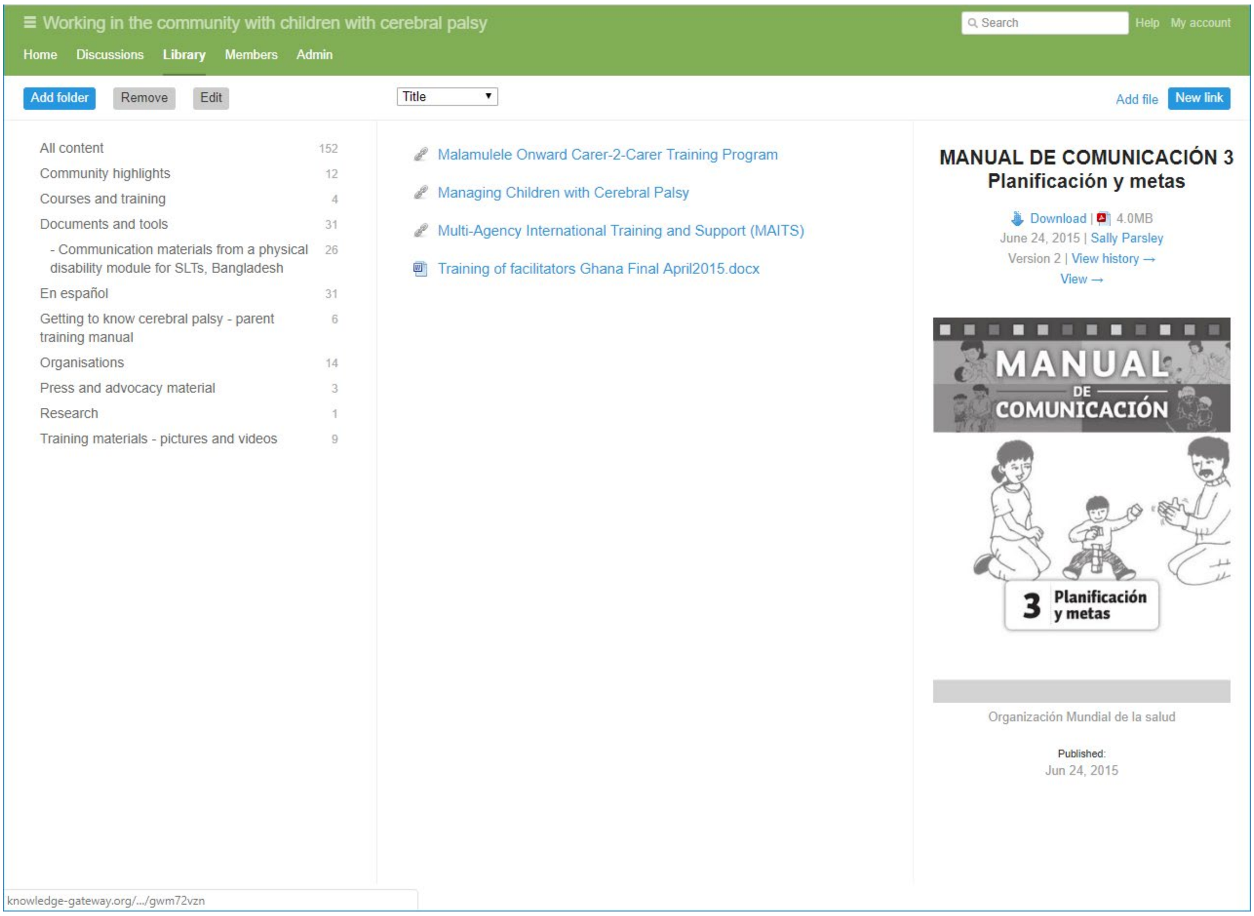
Knowledge Gateway (https://knowledge-gateway.org) from the World Health Organization was selected as the most appropriate online platform for CoP, as it was free and specifically designed to support virtual collaboration and networking for health and development around the world, including settings with limited internet access.

When launched the CoP was facilitated by one member of LSHTM staff who led on the CoP facilitation for 2-3 hours per week and a second member of staff who provided 1-2 hours per week of technical support, over the first 2-year period. Support for the development and management of the CoP was provided by a steering group and a small team of CoP champions. These champions were selected to represent different regions of the world, and their role was to contribute to the moderation of the CoP; the team of five were therapists, CBR workers, or parents.

For the first 18 months after launch, there were regular themed discussions on a three-monthly basis on a variety of topics. These were summarised into "Community Highlights" and were also translated Spanish. An example is in the Appendix.

The purpose of this evaluation is to evaluate lessons learnt from the implementation of the CoP and its ongoing use by members.

Current membership overview (July 2019): 412 members from 72 countries



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Malamulele Onward Carer-2-Carer Training Program

Managing Children with Cerebral Palsy

Multi-Agency International Training and Support (MAITS)

Training of facilitators Ghana Final April2015.docx

MANUAL DE COMUNICACIÓN 3
Planificación y metas

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Jun 24, 2015

knowledge-gateway.org/.../gwm72vzn

Illustration. Screengrab of Spanish materials in the library of the COP's online platform

Methodology

The specific research questions were:

1. What has been the impact of the CoP on members' use of the parent training manual 'Getting to know CP'?
2. What types of human relations, community building, knowledge sharing, and knowledge building activities did the CoP members engage in?
3. What were some of the key factors facilitating engagement and sustained membership of the CoP?

The evaluation used a mixed methods approach to evaluate the views and actions of CoP members who were cerebral palsy practitioners or representatives of supporting organisations (LSHTM/CBM). This consisted of the following methods:

(1) Online baseline and end-line surveys to members of the CoP. Baseline survey carried out 2 months after CoP launch with all members and end line survey conducted between June -October 2018 with all CoP members with >12 months' membership.

(2) Thematic content analysis of all CoP messages sent during a 16 month period between March 2014 and June 2016

(3) Analysis of membership demographics in June 2016

(4) In-depth interviews conducted in 2018 with eight members and key stakeholders, including the CoP Champions. The interviews lasted on average 1 hour, and were recorded, transcribed/notes taken and anonymised before being analysed.

Ethical approval was granted by LSHTM.

Sampling

Recruitment to the base and end-line survey was self-selecting. To support members with low connectivity to respond, surveys were shared as Word documents as well as online surveys.

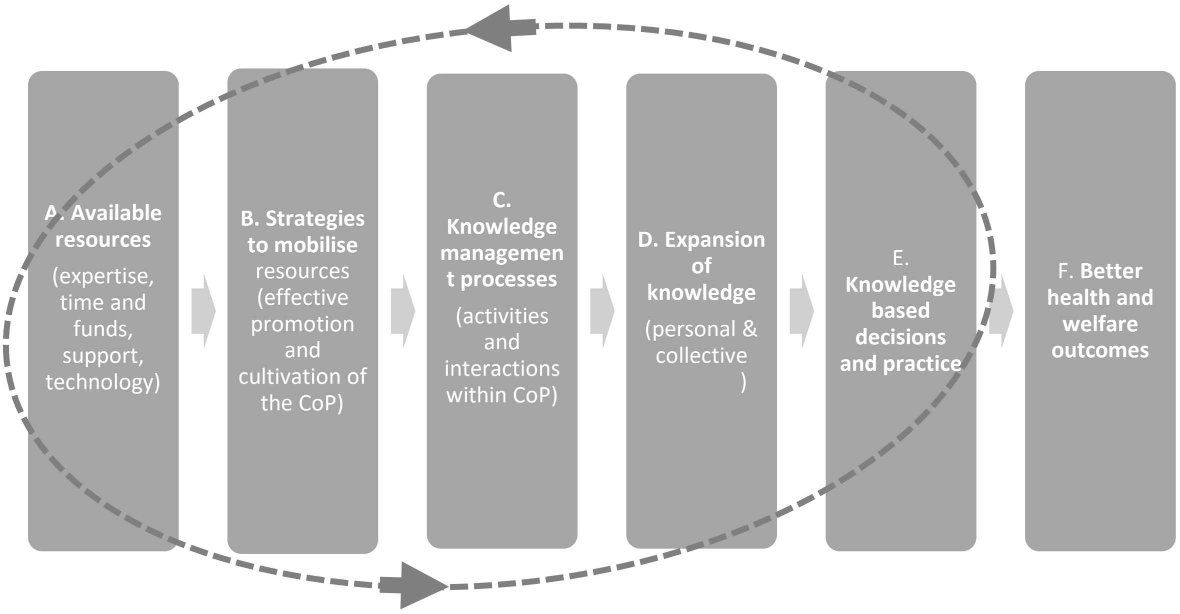
33 respondents working across 31 countries completed the baseline survey. All but one worked in low or middle-income settings and 59% worked internationally across multiple countries or regions. 77% worked for a local or international NGO. Most respondents were female (82%) and half were aged over 40 years (53%). The characteristics of the end-line survey respondents were very similar to the baseline. The 40 respondents were based in 22 countries with 62% in a low or middle-income country and 70% who worked for a local or international NGO. Most respondents were female (82%) and aged over 40 years (82%). 62% worked internationally across multiple countries or regions. 72% had somewhere at work to get support for improving their knowledge and skills around working in the community with children with cerebral palsy.

Purposive sampling was used to select members for the in-depth interviews. The criteria were to include members from low resource and high income settings, some of the disability champions, and members with different levels of activity within the CoP: passive (no messages sent), active (posted 1 or more messages), very active (one of a small group that sent a third of all messages).

Framework & analysis

This evaluation adapted the Bertone & Meessen evaluation framework [3] (see fig A) which organises the key elements of a CoP into a logical flow, linking the availability of human and information resources with members' capacity to access, share and use them to create knowledge, change practice, and ultimately improve in health outcomes.

Fig A. Bertone & Meessen's conceptual framework for assessing communities of practice [3]



In addition, the study applied Gunawardena et al.'s model of the social construction of knowledge online [6] (see fig B) to assess the extent to which interactions in the CoP showed evidence of knowledge sharing and expansion (stages C and D of the evaluation framework).

Fig B. Gunawardena et al.'s interaction analysis model for social construction of knowledge [6]

Phase I	Sharing & comparing of information
Phase 2	Discovery of dissonance and inconsistency
Phase 3	Negotiation of meaning / Co-construction of knowledge
Phase 4	Testing and modification of proposed synthesis
Phase 5	Agreement / Application of newly constructed meaning

Sharing and comparing of information, has been found to be the predominant phase of knowledge construction found in CoP discourse [6]. In our evaluation we also sought to look at how members went on to apply knowledge gained from the CoP (Stage E of the evaluation framework) and also to assess some of the key factors facilitating engagement and membership of the CoP (Stage B of the evaluation framework).

The surveys were analysed in Excel. The content of the postings on-line was uploaded into NVivo 11 software and thematically analysed. One researcher coded all the interviews and then 50% of all the data and coding was reviewed by a second researcher.

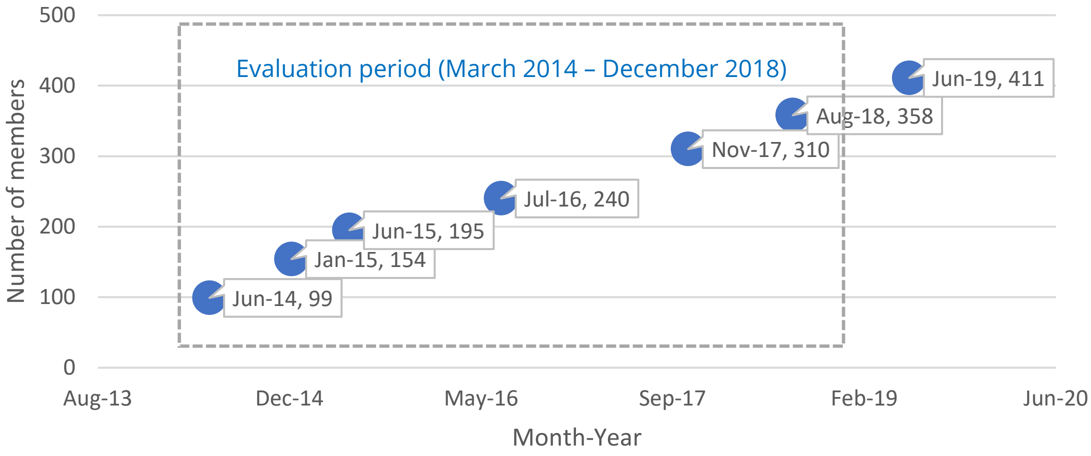
All the in-depth interviews were recorded, and transcribed, and a thematic analysis conducted, also managed using NVivo 11 software.

Findings

Our CoP membership and participant responses

There were 233 CoP members from 57 countries in June 2016, 15 months after launch. 88% were working for an organisation involved in the provision of care for children with developmental disability (e.g. NGO, hospital/clinic, university), and 54% of members were based in 43 low- or middle-income countries. CoP membership continued to increase throughout the study (see fig C) reaching more than 350 members by the end of the evaluation period in December 2018.

Fig C. CoP membership



113 members sent 728 messages to the CoP between March 2014 - June 2016. 48% of members posted at least one message but just 10% of members sent ~70% of posts.

A thematic analysis of the 'units of meaning' at the clause or sentence level in each message sent to the CoP found 1366 contributions of relevance to the outcomes identified in the evaluation framework (see Fig A).

The CoP is used to share knowledge about the GTKCP manual and about working in the community with children with cerebral palsy

In the content analysis we found that sharing (giving and requesting) information was the most common type of contribution with just over a third of all contributions relating to this. The distribution was roughly evenly split between those with direct relevance to the parent training and those of more general relevance to working with children with cerebral palsy or other neuro-developmental disabilities.

> *"In my experience, with the group of children with dyskinetic CP little effort is done to improve their communication abilities. I would be very happy to hear your experiences and materials that can help bring children out of isolation and into inclusion."* ID0153, Ethiopia

The more general knowledge sharing contributions covered a wide range of topics. About half were related to sharing information about resources and training opportunities. And about a fifth were related to requesting or sharing translations of other resources.

> *"I am interested in taking the course. (which I tried already) Once the course is client- friendly again, we would like to ask OT students who are going to do fieldwork in a developing country with children with CP to follow this course as an extra preparation."* ID021, Belgium

Responses to the end-line survey affirmed the importance of knowledge sharing to members. 80% agreed or strongly agreed that the CoP was an important place for them to discuss issues about working in the community with children with cerebral palsy and 67% felt that the CoP was an important way to share their own knowledge on this topic.

In terms of sharing knowledge about how the parent training was being used, a key theme was **reassurance and encouragement** from hearing how others were using the manual. This was a common theme in the interviews.

> *"It has really improved my own knowledge, because I now know this lady in in South Africa, the one doing the equipment I've forgotten her name, and meeting such people [on-line] has made me feel that I'm on the right track" (Code 02, parent and director of local CBO)*

Participants highlighted that finding out '*what others are doing and finding out what is possible*' was one of the main benefits of the CoP. For two of the interviewees, they found it **most useful at the start** of the roll out of the manual and it became less important over time as they became more familiar with the training.

> *"I think it was very relevant for me for the first year really to understand how people were using the material, and what was their feedback, and then slowly it became less relevant because I have worked with the material and I have used it, so now I am more confident." (Code 01- INGO Advisor)*

The CoP is used to increase access to human and information resources

The content analysis showed that sharing resources was the second most popular community activity with just under a third of all contributions relating to this. These could be broken down into two main sub themes:

Sharing information resources, including: the GTKCP manual, educational resources relating to cerebral palsy and child disability, educational resources in other languages, practice-based images and photographs, links to websites and organisations, research information, training opportunities, advocacy material and job opportunities.

> *"My colleague in Kathmandu did tell me in May 2014 that the CBM manual was translated by the Hospital and Rehabilitation Centre for Disabled Children (HRDC). I do not have contact details for the service/person in charge, but here is the centre web address: http://www.hrdcnepal.org/?option=research"* ID0045, Belgium

Networking opportunities, including requests for contacts, networking opportunities, opportunities for further direct contact online or in person

> *"There is a session at the Stockholm meeting on Thursday 2nd June between 17-00 and 19-00 to discuss the survey findings, discuss ideas and the way forward with this initiative. I think the members of this group would have a lot to offer and request all those who are attending the conference to try and attend. It would also offer the opportunity for members of this group to meet, catch up and share ideas."* ID0027, UK

The end-line survey corroborated these findings, demonstrating the value of the CoP in promoting access to resources, in particular the GTKCP manual, to members and their colleagues outside the CoP.

Improved access to the GTKCP manual:

- 93% had downloaded the manual and all but one had gone on to use it.
- 67% rated the manual as one of the most useful resources shared in the CoP.
- 52% had shared the manual with colleagues.

- 20% reported being involved in translating the manual. Translation into eight languages was reported (Chichewa, Tamil, Vietnamese, French, Kinyarwanda (Rwanda), Kiswahili, Bangla and Chinese) as organisations came together, facilitated by the CoP, to conduct jointly funded translations

Improved access to other informational resources:

- 80% of respondents agreed that being a member of the community had helped them access new materials and resources
- Access to new resources (67%) was the most popular reported benefit of CoP membership.
- And 42% had used to the CoP to share their own materials and resources.

Improved access to human resources:

- 80% had made new connections at least partly through the community
- 52% had gone on to network further with other members
- 42% had made a new contact
- 15% had met face to face with other members in person after connecting in the CoP.

Improved access to others' expertise (59%) and help to connect to and network with others (39%) were two of the most popular reported benefits of CoP membership. The value of connecting people with a shared interest in working with children with CP was a strong theme throughout the end-line survey:

> *"It is an excellent and unique resource linking parents, practitioners and experts worldwide. It allows informed debate."*

The content analysis found a small number of contributions which directly demonstrated that members were applying what they were learning in the CoP to their practice around parent training:

> *"I have been following the thread of conversation over the last couple of days and find the information quite helpful, as I am now organizing the first parent training for Jamaica using the Manual. The training will be held during the first quarter of next year. I have made a note of the recommendations shared and will seek to adopt them into this experience."* ID0052, Jamaica
>
> *"Hello […], thank you for the links you sent me are very interesting for we are initiating a process in Colombia with Indigenous population, victims of conflict and disability, which are located in remote and inaccessible locations…"* ID0042 Colombia

Whilst the end-line survey found that nearly half (46%) respondents agreed or strongly agreed that they had made changes to their working practice using knowledge gained from the CoP. In addition:

- 20% had used the GTKCP manual for running parent groups, as intended. Interestingly, 62% had used the manual for general training of staff and community volunteers
- 20% stated they had used the GTKCP manual for advocacy with decision makers about services for children with CP.

Finally, across all the in-depth interviewees, the human networking element of the CoP was highlighted as the most important benefit: '*of most use is the contacts that I've been able to make*'.

> *[I have] developed new connections – I've connected with a professor from Canada – he very supportive in developing the programme. [He has] inputted into the document (Code 05 NGO professional, Rwanda)*

Aside from more general **global networking**, engaging with the CoP had frequently resulted in members finding people to contact from within a country. This had often opened up other avenues of support, such as information on relevant training courses, access to trainers in one country, and funding opportunities, for example.

> *This resulted in personal contact with the Presbyterian Church of Ghana – this has resulted in one of my group being sponsored to follow a training course on APT (appropriate paper technology). This mother is now training to other students, and she is making the Medina centre (a special centre within a school) a resource centre for APT. (Code 2, Parent & local NGO director)*

What people valued was that it was a safe place to share questions and materials, where people '*spoke the same language'*. One of the interviewees reflected on the fact that he has never posted, but didn't feel the need, as he got what he needed from the CoP:

> *People speak the same language. ……….I have never posted – not because I don't want to, but I have not got to. It has opened the door to a hidden population of therapists in resource constrained settings. I find new solutions to working in resource constrained settings – where 90% of world's kids are. (Code 05)*

It was the combination of networking and access to resources which was attractive as illustrated here by one interviewee:

> *The CoP can be used to find ways to bring expertise and resources together, it allows the little man with lots of lived experience to access scientific research, knowledge and to share their own. Its strength is in offering a space to share diverse opinions in a non- confrontational way (Code 05)*

There was wider sharing of resources summarised in the quarterly Highlights; these Highlights summarised a discussion on a particular theme and encouraged the wider sharing of relevant resources. Overall eight Community Highlights were produced on a range of the following topics: Assistive Devices, Advocacy, Toileting, Drooling, Communication, Feeding & Nutrition, General (July-Sept 2014), General (March- May 2014). An example Highlight on Drooling is included in the Appendices.

Participation in the CoP contributes to expansion of knowledge and skills and improved delivery of training for parents

The content analysis found a limited number of contributions to the CoP that showed evidence of members co-creating knowledge together through messages to each other in the CoP. Most, but not all, of these discussions related to the GTKCP manual and were initiated and facilitated by the LSHTM facilitator or by community champions. The quote below is from a discussion led by the LSHTM facilitator discussion on toileting:

> *"It has been great to follow the discussion about how to adapt a chair for toileting needs for children with CP. I think it is also important to think about the implications if a child cannot use a toilet independently and is either left lying in her own urine, or not dressed because she soils the clothes and has no opportunity to participate in other activities at home and so on. As was mentioned the problems with going to school*." ID0001 Uganda

The content analysis only provides a limited insight into actual knowledge expansion from engagement with the CoP. For instance, individual reflection on CoP messages which leads to new understanding / knowledge creation is not captured. The social construction of knowledge through in-depth discussion was also taken outside this CoP as members got in touch with each other individually or - as in one case - a small working group established itself to pilot a new training resource.

In the end-line survey, 77% of respondents emphasised (agreed or strongly agreed) that the 'Community Highlights' (summarised digests of community discussions in English and Spanish) were a useful way to learn.

Overall, 88% reported that the online community was one of the main networks they used to support their work, and/or thinking, about working in the community with children with cerebral palsy.

Around half agreed or strongly agreed that participating in the CoP had contributed to expanding their knowledge and skills and changing their attitudes around working in the community with children with cerebral palsy:

- 51% that it had helped them increase their skills
- 44% that it had challenged some of their attitudes.
- 42% that it had helped them expand their knowledge
- 35% also reported that they had directly used the GTKCP manual to update their own knowledge.

In the in-depth interviews, 'knowledge building' was closely related to the practical aspects of implementing the GTKCP manual. This may have been because most of those interviewed were in quite senior positions and/or in advisory roles and so were not looking to build their experience around management of children with cerebral palsy.

> *" I remember one thing I thought was I needed was a toolbox- the things you need to actually run the training, the essentials (materials, small local toys). …….I brought this up in the discussion. I also discussed, what are the 'must haves' when you are running the training, for example, a good translator. So, I think I brought it up." (Code 02)*
>
> *"If I had to run another training in a different country, I would go back to the CoP and say "who has experience in this country that I can steal. (Code 01)*
>
> *The feedback from parents has really influenced my thinking (Code 06)*

Enabling and constraining factors which affect participation in the CoP

Two main themes emerged as contributing to positive participation in the CoP:

A safe and supportive environment.

In the content analysis, a significant number of postings (about an eighth of all contributions) included positive feedback and thanks to the group and individuals for sharing experiences.

> *"...thank you for sharing the details of this project in Uganda. I am excited to hear more about your work - the income generating activities must be rewarding work, and inclusion is a wonderful aim."* ID0061, UK.

In the interviews the CoP was described as a 'non-confrontational' forum for sharing information, where people 'spoke the same language'.

And in the end line survey, 95% were positive that the community provided a supportive learning environment. 75% felt that the level of support provided by the community for working in the community with children with cerebral palsy was good or very good.

Sharing materials in other languages, and the Highlights in Spanish were also seen as a positive, facilitating factor. 18% agreed in the end-line survey that communications being mostly in English was sometimes a barrier to participation.

Members felt comfortable to be passive. It was clear that many were happy to be largely passive in their membership, reflected in the interviews and survey:

> *"I have been reading more than contributing to this forum enjoying and benefiting from the rich experience this forum brings."* ID0153 Ethiopia

The CoP platform and support were acceptable.

Quick resolution to technical issues. A small number of postings related to technical and practical issues hindering participation in the CoP; these all received support from the LSHTM technical support member and were generally quickly resolved: *"Dear all I cannot find the link to the Chichewa Manual Please could you help."* ID01030, Malawi.

And in the end line survey, 82% felt that the Knowledge Gateway platform was a user-friendly communication platform.

Discussion

This evaluation triangulated various pieces of evidence to explore the role and impact of an on-line CoP 'Getting to know Children with CP". It explored resource and knowledge sharing and knowledge building in support of the roll out of a training manual 'Getting to know cerebral palsy'. We showed that the overall objectives were met, but that there were also additional benefits to the CoP which had not been envisioned.

Our evaluation indicates that the main impact of participation in the CoP for members was reduced professional isolation through increased access to resources; both information and human. In particular, the value of networking to members comes through strongly as an important benefit of participation.

The evaluation also demonstrated a positive impact on increased knowledge and skills, change in attitudes and changes to practice around the use of the GTKCP manual. However, although the original aim was for the CoP to support the roll out of the manual, it was also clear that it was equally as common for a broader range of issues to be raised about working with children with cerebral palsy. In fact, some members of the CoP had joined without being aware of the training manual and membership of the CoP then facilitated access to the manual.

The evidence of knowledge expansion or application to practice found in the content analysis was weaker than reported by members in the end-line survey. This may be because, as found in this study and as reported in other studies [7], the majority of CoP members prefer to be passive members or to 'lurk' and learn from others' messages rather than engage in active discussion in online communities. This makes it more difficult to therefore evaluate the level of knowledge expansion.

In terms of facilitating factors, it was shown that there was a positive and supportive environment for the postings onto the community. Although members did experience a number of technical issues, these were quickly responded to by having a dedicated technical team member.

What was less clear from the evaluation what the role of the champions was in facilitating discussions and promoting more engagement in their regions. This would require further investigation in any future development of the CoP.

The findings indicate the importance of actively managing and leading the CoP in balancing members and stakeholders' interests to build collective reflection, agreement and activity towards commonly agreed desired outcomes [8].

Strengths and limitations of this evaluation

This evaluation used a number of mixed methods to understand the relevance and impact of the CoP, and therefore by triangulating the results we were able to build up a fuller picture. The survey was with a self-selecting sample of respondents in the surveys, and they may have been likely to comment positively, but the thematic content analysis of the postings over 16 month period also illuminated what was actually shared in practice.

The use of the evaluation framework and interaction model to analyse social knowledge building within the CoP enable the findings to be assessed against those found in other contexts. A future piece of research should further examine the wider personal and structural factors which affect who joins and how they are able to participate and benefit from an international knowledge sharing CoP [9], [10].

Recommendations and next steps

This section is a synthesis of recommendations collected from the end-line survey, in-depth interviews, and an overall analysis of the data. If the CoP is to continue, then some of these would require further discussion and elaboration:

- 90% of respondents in the end-line survey and all those interviewed want the community to continue.
- 70% of those surveyed want the CoP to expand its remit to include children with other neurodevelopmental issues. This was also a key issue for those interviewed.
- Promote and integrate the GTKCP manual more effectively within the CoP.
- Provide more facilitation and support for effective, relevant participation within the CoP. Ideas shared were:
    - A facility to review resources before being shared, to ensure quality
    - More clarification that the CoP is focussed on low income settings and/or provide separate streams for a focus on higher income setting
    - A sub-platform for different regions to enable more local discussions and address language barriers.
    - Support for more networking opportunities for members, online and offline
    - Help for members with specific information search needs
- Consider membership fees to help maintain the group, in particular for the larger INGOS

It was less clear from the evaluation what the role of the champions was from the evaluation, and this would need further investigation in any continuation of the CoP. The role of 'Champion' is likely to require more ongoing investment if it is to facilitate ownership of the CoP.

In terms of managing the ongoing leadership of CoPs, other studies have shown that it can be a challenging task in informal online CoPs [11]. For example, in this CoP, leadership resourcing ended with the completion of the research project in 2016. The effects included the end of the thematic Community Highlights and steering group meetings.

Based on our experiences we recommend including a clear 'CoP life cycle' plan during the initial planning stage which is shared with members during and after launch. The plan should include:

- a transition strategy to enable the CoP to close in an orderly way or to continue and grow with new leadership or funding
- a small, ongoing resources budget for some regular facilitation and to support transition periods

And finally, we also recommend that the CoP evaluation framework should be adapted and expanded to include consideration of the wider personal and structural factors that influence who, why and how members from a wide variety of organisations, settings and roles, join and participate in this kind of CoP.

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Appendices

Appendix A. Example of a Community Highlights document from the CoP

Community Highlights documents summarised regular themed and facilitated discussions within the CoP.

Community Highlights: Drooling

June 2016

This edition of highlights is to summarize the discussion on Drooling that took place from May-June 2016

Thanks to our members for continuing to introduce interesting and important topics for discussion. We encourage everyone to continue bringing new topics forward to the group.

Best Wishes,

Maria, Sally and Kelly

[Contact us through the group or directly at maria.zuurmond@lshtm.ac.uk]

Current Membership

237 Members in 58 Countries

Key Topics Shared

Marjolein shared her experience in Ghana where there seemed to be a lot of stigma attached to drooling. She presented the possibility that this stigma is linked with misunderstandings of cerebral palsy, and the idea that it is an infectious disease spread through bodily fluids.

In response to this finding, Marjolein was looking to the group for support with:

1. Strategies for preventing drooling and improving muscle control
2. Approaches for sensitizing community members.

TOPIC 1: The community members generated the following advice on strategies for preventing drooling:

- ✓ Community member shared that a field officer in Burkina would carry plastic gloves in order to stimulate the mouth of the child with CP. Similarly, it was suggested that: Teeth cleaning, with the fingertip or a brush can help normalize sensation if the child is hypersensitive.
- ✓ Gently stroke child under the chin- they will reflexively close the mouth.
- ✓ Trunk and head position are a good place to start before looking at the mouth. Make sure the head is in alignment with the trunk and reduce neck extension, which encourages an open mouth.
- ✓ Do not keep wiping mouths, dabbing is better and can encourage lip closure if it can bring the bottom lip up to meet the top lip.
- ✓ Squares of material (patterned) that disguise the presence of saliva may also help with social acceptance.
- ✓ When feeding with spoon resist the urge to scrape the food off the spoon with the child's front teeth, which tends to encourage tongue thrusting and drooling.
- ✓ SLT reported getting the child to start using a straw while drinking to encourage her to close her lips (While she has her lips closed to suck I show her her face in the mirror and point out to her that she has indeed closed her lips, with a whole lot of fuss and congratulations. The eventual aim of course is to reduce drooling and enable her to achieve lip closure for speech.
- ✓ Give the child exercises like blowing out a candle at bedtime.
- ✓ Suggested resources: GTKCP manual, David Werners' Disabled Village Children (chapter 35/ pages 314-315 (on drooling support))

TOPIC 2: Approaches for sensitizing community members.

This topic remains open for discussion.

Drooling- Summary of New Resources Shared

- Request made for video clips or photos that can be used as visual aids for parents.

- Drooling Dropper (saved in community library)- this outlines a method for reducing drooling using an eye dropper.
- http://www.rch.org.au/uploadedfiles/main/content/plastic/salivabook.pdf - Saliva control handbook

Moving Forward:

- Received requests for the manual in Kiswahili (Sue responded to this request- an early version is available but requires updates).
- Research on Getting to Know CP in Tanzania- any interested partners?

Champions

Champions are leaders who facilitate knowledge sharing in their community, and can be country or topic specific. We hope for our champions to check in on the forum regularly, post issues for discussion, contribute, and share ideas on ways to improve the community of practice. We ask you, colleagues, for your thoughts on ways to foster a strong community ethos.

Please get in touch with Maria if you are interested in becoming a community champion. Maria.Zuurmond@Lshtm.ac.uk

- Gonna Rota, Asesora, CBM, Guatemala
- Joerg Weber, CBM
- Maria Regina Zulianello, CBM, Nigeria
- Maria Zuurmond, LSHTM, UK
- Marjolein Meande Baltussen, CBM, Ghana
- Michiel Steenbeek, CBM
- Sally Parsley, Technologist, LSHTM, UK
- Sue Fry, Motivation Africa, South Africa
- Christine Tusiime, CoRSU Rehab Hospital, Uganda

Extra resources on the community website

We have a community website that is open to all registered members at https://knowledgegateway.org/workingincommunitychildrencerebralpalsy/

The site has some features you may find useful:

- An archive of all the discussions to help you find old conversations
- A library of resources: we encourage members to add resources to the library
- A map of members: this is helpful for identifying members based in your region or country

Contact Sally, Sally.Parsley@LSHTM.ac.uk if you have problems using the website

Appendix B. Evaluation framework for the online community of practice, "Working in the community with children with cerebral palsy"

Adapted from Meessen & Bertone [4]

Outcome	Indicators
CoP is used to share knowledge about the GTKCP manual and working in the community with children with cerebral palsy	• Number of community posts • Number of members posting • No. of posts sharing or comparing information about the parent manual and working with children with CP
CoP is used to increase access to human and information resources	Number of posts evidencing: • Sharing of information or materials Reported increases in: • Sharing & access to information or materials • New contacts made • New networking opportunities • No. of CoP members
Participation contributes to expansion of knowledge and skills	• Number of posts evidencing Phases 2 -5 of Gunawardena et al.'s interaction analysis model of online social learning [6]
Participation contributes to improved delivery of training for parents in a community setting	• Examples of application of learning or problem solving from CoP to practice, relating to the manual • Number of translations of the manual
Enabling and constraining factors affecting participation in the CoP	• Benefits and expectations of CoP • Factors affecting participation - shared language, trust, nationality, user-friendliness, leadership/Champions, sense of belonging, use of platform • Financial support for CoP

Appendix C. Interview sampling framework.

Category (n=no. of members)	1. Local & very active (n=1)	2. Local & active (n=53)	3. Local & passive (n=72)	4. International & very active (n=5)	5. International & active (n=52)	6. International & passive (n=43)
Target no of interviews	1	3	3	1	2	2
Actual no. of interviews	1	3	2	0	1	1