



www.childhealthservicemodels.eu
@ChildMOCHA_EU



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

June 2018

Volume 4, Number 1

In This Issue

- Welcome
- MOCHA Final Conference
- April External Advisory Board Meeting
- Meeting with Key Irish Stakeholders
- Medical Informatics Europe conference 2018
- WONCA Europe 2018
- 4th PNAE Congress on Paediatric Nursing
- Webinar: Models of Care Delivery for Children with Medical Complexity
- Children in the Care System
- Children in out-of-home care
- European Health Management Association Conference
- Project news

Welcome

We are now into the last few months of the MOCHA project. It doesn't seem that long since we first started on this journey, and yet we have achieved so much new knowledge about how children and young people use primary care services in the EU and EEA, and how the primary care services meet (and sometimes fail to meet) the needs of our children. We have had a busy few months as we continue to refine our key messages from the project, present our work at various conferences and prepare to present our findings and recommendations at the end of the project in November. At the same time, we are looking to the future MOCHA is stimulating an impetus to improve primary care services for children and recognise the needs of children in Europe, and we don't wish this to cease.



MOCHA Final Conference

You are welcome to join us for the presentation of results at MOCHA's final conference, to take place on 15th and 16th November 2018, in The Hague, Netherlands. The conference will share headline results, introduce the formal reports, enable stakeholder discussion on next steps after the project's conclusion.

Presentation of key MOCHA findings

Invisibility of children in data and policy systems; measurement challenges; listening to young people; vulnerable children and equity; delivering complex care; patients and primary care interfaces; school and adolescent health services; health workforce in child health; education of the health workforce; e-health as the enabler; optimum service models.

The Way Forward for Primary Child Care Health in Europe

Understanding child centricity; Bringing MOCHA results to local services; contextualising into European and Professional Initiatives

To book a place, please follow this link

<https://www.boerhaavecontinuousmedicaleducation.com/medical-extensions/2018/models-of-child-health-appraised-final-conference-presentation-of-results/>

MOCHA Partners

Imperial College of Science,
Technology and Medicine,
London UK

Trinity College Dublin
Ireland

University College Dublin,
Ireland

University Medical Center
Groningen, Netherlands

Consiglio Nazionale Delle
Ricerche, Italy

University of Surrey, UK

Karolinska Institutet, Sweden

TNO The Netherlands Organisation
for Applied Scientific Research

King's College London, UK

Universiteit Maastricht,
Netherlands

Uniwersytet Medyczny w Lublinie,
Poland

UiT The Arctic University of
Norway, Norway

Haskoli Islands, Iceland

European University of Cyprus,
Cyprus

Universiteit Twente, Netherlands

Syddansk Universitet, Denmark

University of Keele, UK

Boston Children's Hospital, United
States

Hospices Cantonaux, Switzerland

Murdoch Children's Research
Institute, Australia

April External Advisory Board meeting

The final face-to-face meeting of the External Advisory Board and the last formal physical meeting of the work package leaders of the MOCHA project took place in Tallaght, Dublin on 17th -20th



April 2018. We

were warmly welcomed to Trinity College Dublin by Associate Professor Maria Brenner and her team from Work Package 2, and enjoyed the excellent facilities at the Institute of Population Health, Trinity College Dublin.

At the meeting, we had the opportunity to discuss the progress we had made since our October 2017 meeting in Riga, Latvia. This included reviewing our emerging results from the separate work packages; and discussing these in terms of how they cross over the different disciplinary and research interests in the project. We emerged with some preliminary 'headline messages', with which we could then hold a thematic discussion with our external board. The External Advisory Board, as ever, gave us very valuable and insightful critique, and we

discussed together the implications and potential for unintended consequences of what we are discovering about children's primary care services in the EU and EEA countries.

We also held many specific discussions about the different methods of appraisal and how to choose the most appropriate for such a complex issue as primary care for children. As we have done for the past year, work packages are working very closely together to understand how the elements of primary care interweave to provide health services, and to understand how this affects the health of children.



Meeting with key Irish stakeholders

On the 18th April, Leaders of the MOCHA project were welcomed by Prof Brenner at a formal dinner held at the 1592 Restaurant at Trinity College Dublin. This was a rare opportunity for us in the project to gain feedback on our work with key leaders in health and children's interests in Ireland. We enjoyed meeting Katherine Zappone, Irish Minister for Children and Youth Affairs, and leaders from the Irish Health Services Executive, Department of Health, Senior nursing officers, academic officers and Prof Mary McCarron, Dean of the Faculty of Health Sciences at Trinity College Dublin. This was an extremely rewarding event, at

MOCHA Work Packages

- 1: Identification of Models of Children's Primary Health Care. Lead: Prof Mitch Blair
- 2: Safe and efficient interfaces of models of primary health care with secondary, social and complex care. Lead Prof Maria Brenner
- 3: Effective models of school health services and adolescent health services. Lead Prof Danielle Jansen
- 4: Identification and application of innovative measures of quality and outcome of models. Lead: Dr Nadia Minicuci
- 5: Identification and use of derivatives of large data sets and systems to measure quality. Lead: Prof Simon de Lusignan
- 6: Economic and skill set evaluation and analysis of models. Lead: Prof Heather Gage
- 7: Ensuring equity for all children in all models. Lead: Prof Anders Hjern
- 8: Use of electronic records to enable safe and efficient models. Lead: Prof Michael Rigby
- 9: Validated optimal models of children's prevention-orientated primary health care. Lead Dr Paul Kocken
- 10: Dissemination. Lead Prof Michael Rigby
- 11: Project Management. Lead: Prof Mitch Blair

which many connections were made and important issues discussed, which gave us a fascinating insight into the transferability of our results to one EU country, and thoughts about how our work has the potential to impact on real practice and services for children.



Left to right: Ms Eilish Hardiman, CEO Children's Hospital Group; Prof Mitch Blair MOCHA, Prof Mary McCarron TCD, Minister Katherine Zappone TD, Dr Martin Weber WHO, Associate Prof Maria Brenner TCD, MOCHA; Prof Anne-Marie Brady, Prof Michael Rigby MOCHA.

Medical Informatics Europe conference

Professor Michael Rigby represented MOCHA at the recent Medical Informatics Europe conference, in Stockholm on the 24th – 26th April 2018. Our three contributions from our Work Package 8 research into electronic health records were well received: **Variation of National Policies on Controlled Sharing of Children's Primary Care Data** (Rigby M, Greenfield R, Kuhne G, Majeed A; Blair M); Rigby M, Greenfield R, Kuhne G, Majeed A; Blair M (Rigby M, Greenfield R, Kuhne G, Majeed A; Blair M), and **Children's EHRs in Europe – need for development of international standards on data sets and functionality** (Rigby M, Greenfield R, Kuhne G, Majeed A; Blair M). At the conference the opportunity was taken to host a joint workshop, triggered by MOCHA ideas, but organised by the HL7 Foundation (<http://www.hl7.org/>) as coordinators of the Trillium project (<https://trillium2.eu/>). Up until MOCHA's intervention, children had not been considered in their work. At our suggestion, the European Centre for Disease Prevention and Control (ECDC) were also involved in the workshop, which has subsequently triggered an action plan to commence in the autumn 2018.

WONCA Europe 2018

Professor Mitch Blair represented MOCHA at the recent World Family Doctors WONCA Europe conference in Krakow, Poland (www.woncaeurope2018.com). Professor Blair presented a 75 minute workshop on MOCHA entitled **A critical analysis of variations in provision of primary health care for children and young people in Europe**. In this workshop he presented four linked interactive sessions, covering the development of the child centric appraisal model and suggested refinement of the PHAMEU primary care framework;

findings of the systematic review and meta-analysis comparing primary care paediatrics and family practice models in relation to prevention, age at diagnosis and effective care of chronic and complex disease in children and young people; Thematic analysis of interface issues for children with complex physical and mental health needs; and policies and use of electronic health records and the potential impact of infrastructure affecting delivery of primary care to this population. Although the attendance to the workshop was not as large as we hoped, a good discussion was had, particularly about the poor focus on children in many policy development and data items.

Professor Blair also represented fellow MOCHA researcher Dr Kinga Zdunek, who is currently on maternity leave; by presenting her paper on **Societal reactiveness to the child health policy issues in Europe**. The presentation was well received, and stimulated some interesting discussions afterwards.

4th PNAE Congress on paediatric nursing

Associate Professor Maria Brenner was an invited speaker to the 4th Paediatric Nursing Associations of Europe (PNAE) Congress on paediatric nursing, held on the 1-2nd June in Athens, Greece (www.pnae2018.org). Professor Brenner discussed the issue of nursing and our findings about the role of nursing in MOCHA, particularly for children with complex care needs who require nursing in the community, and interface with primary care services alongside secondary and tertiary care input to meet their health needs. The presentation was extremely well received, and garnered much enthusiasm about drawing together issues for nursing across MOCHA, we look forward to the PNAE further endorsing our work as we complete the MOCHA project.



Webinar: Models of Care Delivery for Children with Medical Complexity

Associate Professor Maria Brenner was a guest speaker in a webinar conversation on June 28th discussing **A Conversation on Models of Care Delivery for Children with Medical Complexity** in conjunction with the Lucile Packard Foundation in the United States. It was extremely well received, with over 450 people listening and contributing in the United States and in Europe.

Prof Brenner was invited to discuss how improvements in care delivery for children with medical complexity are becoming a major focus of national and local health care and policy initiatives in the United States and Europe. A number of new models have been developed, with promising examples of enhanced care coordination and family engagement. Prof Brenner drew upon the MOCHA project to give describe the situation in Europe and give recommendations for the

Contact Us

www.childhealthservicemodels.eu

christine.chow@imperial.ac.uk

d.alexander@imperial.ac.uk

future. The discussion was based on the article: **Models of Care Delivery for Children with Medical Complexity** available at www.lpfch.org/publication/models-care-delivery-children-medical-complexity. You can listen to the conversation again at www.lpfch.org/cshcn/building-systems-work-children-complex-health-care-needs. Other speakers were Elisabeth S. Pordes, MD, MPH, Children's Hospital of Wisconsin; and David Bergman, MD, Lucile Salter Packard Children's Hospital. The event was moderated by Rishi K. Agrawal, MD, MPH, Northwestern University Feinberg School of Medicine

Children in out-of-home care

Professor Anders Hjerm's work into equity and children's primary care services has led to a focus on children who are in out-of-home care as an important population group that is vulnerable to experiencing inequity of care. Their task report **Health Care for Children in Societal Out of Home Care** is now available on the MOCHA website (www.childhealthservicemodels.eu/publications/technical-reports). This work will form part of a thematic edition of the **International Journal of Social Welfare**, due in October 2018; with Prof Hjerm and Dr Bo Vinnerljung as guest editors.

European Health Management Association conference

MOCHA was well represented at the recent European Health Management Association conference (<http://ehma.org/events/annual-conference/>), held in Budapest on 20th-22nd June 2018. The theme of the conference was "Making it Happen", and focused on delivering change and overcoming challenges in policy implementation.

MOCHA presented three papers, all of which were unique and attracted much interest because of their focus on novel key issues. Dr Kinga Zdunek's paper entitled **Evidence-based approach to child health policymaking. European perspective** (Dr Kinga Zdunek, Prof Michael Rigby, and Prof Mitch Blair), which was presented by Professor Michael Rigby, was very well received, highlighting new issues and prompting a discussion of enlarging the subject of co-creation of policy in a future conference. Our paper entitled **Accreditation mechanisms for eHealth as a health promotion tool** (Prof Michael Rigby, Prof Mitch Blair, and Miss Shalmali Deshpande) opened the e-health stream at the main auditorium, and outlined the lack of protection against poor advice and hidden data recording in apps and websites designed for children in many countries.

Dr Anne Clancy's paper **Identifying training requirements for nursing children with complex health care needs in the community: A European study** (Dr Anne Clancy, Dr Elena Montañana, Dr Maria Brenner, Dr Michael Rigby, and Dr Philip Larkin) discussed the lack of specific training that many nurses have in paediatric care, even though they care for children with complex care needs in the community.

In addition, three MOCHA posters were displayed in the conference: **Differences in key elements of primary care models to inform an appraisal framework for primary care for children** (Dr Denise Alexander, Professor Michael Rigby, Professor Mitch Blair); **The**

Contact Us

www.childhealthservicemodels.eu

christine.chow@imperial.ac.uk

d.alexander@imperial.ac.uk

coordination of care for children with intractable epilepsy across the EU/EEA: A MOCHA study (Dr Elena Montañana Olaso, Dr Jay Berry, Dr Maria Brenner, Prof Michael Rigby, Dr Miriam Pauline O'Shea, Prof Philip Larkin, and Ms Rebecca McHugh). and **European patterns of child-focused health policy** (Dr Kinga Zdunek, Prof Michael Rigby, and Prof Mitch Blair). All of which generated many comments and discussion.

Public participation

We were really pleased to receive 2403 responses from the general public, from five countries to a questionnaire we ran about the perceived quality of primary child health care and the prioritisation of care characteristics. Thank you to all the participants. The results of the survey will inform part of MOCHA's work in appraising the primary care systems.

Project News



Professor Philip Larkin moves to Lausanne this summer, to take up post as the Kristian Gerhard Jebsen Chair in Palliative Care Nursing and Academic Director of the IUFERS at University of Lausanne. We wish him all the best in this exciting new post.

Farewell and good luck to Dr Miriam O'Shea who has left the project to take up a new post in University College Dublin. Also we wish all the best to Rebecca McHugh who is due to leave the project in July for new adventures.



Many congratulations to Dr Elena Montanano Olaso on the safe arrival of baby Roberto, to Dr Tamara Schloemer who has welcomed baby Marieke, and to Dr Kinga Zdunek who welcomes baby Ewa.



Contact Us

www.childhealthservicemodels.eu
christine.chow@imperial.ac.uk
d.alexander@imperial.ac.uk

Email newsletters privacy notice

Imperial College London ("we" or the "College") provide various newsletters via email about our activities, services and achievements. This privacy notice explains how we use your personal data when you sign up to receive the MOCHA Quarterly Newsletter containing project updates (the "Newsletter").

Why we process your information

If you opt-in to receiving the Newsletter, we will ask for your:

- first and last name
- email address

Our legal basis for processing your personal data for the purposes of sending you the Newsletter via email is based on your consent - by consenting to receiving the Newsletter via email you are giving us permission to process your personal data specifically for the purpose of sending you the Newsletter via email.

You may withdraw consent at any time by emailing MOCHA Project Manager (christine.chow@imperial.ac.uk) with "Unsubscribe" in the subject heading.

Sharing your personal information

We may share your personal data with service providers who assist the College in the preparation, distribution and/or administration related to the Newsletter. Our legal basis for sharing your data in this way is that it is

necessary for our legitimate interest in providing you with the Newsletter.

All our service providers are required to take appropriate security measures to protect your personal information in line with data protection laws. We do not allow our service providers to use your personal data for their own purposes. We only permit them to process your personal data for specified purposes and in accordance with our instructions.

Some service providers may process your personal information outside the European Economic Area. Where this is the case, you can expect a similar degree of protection in respect of your personal information and your personal information will only be transferred where the transfer is permitted under the law.

For example, we currently use:

- Wordpress – We use Wordpress to build and manage the website. For more information please see - [Wordpress Privacy Notice](#).

Except as explained above, we will not share your information with anyone, unless where required by law, where it is necessary to administer our relationship with you or where we have another legitimate interest in doing so.

Keeping your personal information

Your personal information will be deleted from our systems when you unsubscribe from the Newsletter.

Your rights

You have the right to:

- receive a copy of the information we hold about you in a reasonable format specified by you, including for the purpose of transferring that data to another data controller;
- request us to erase your personal data or object to our processing of your personal data;
- request your information be changed if you believe it was not correct at the time you provided it; unsubscribe

If you are not satisfied with how we are processing your personal data, you can raise a concern with the Information Commissioner: www.ico.org.uk

If you have any concerns with regard to the way your personal data is being processed or have a query with regard to this information, please contact our Data Protection Officer at:

Imperial College London Data Protection Officer Exhibition Road Faculty Building Level 4 London SW7 2AZ e-mail: dpo@imperial.ac.uk