



DIPEX International

NEWSLETTER



Introduction from the chair

Dear Colleagues,

Welcome to our annual Newsletter. Despite another tumultuous year around the globe, our DIPEX community has stayed strong and answered the call for focusing on that most important aspect of health and illness – patient experiences. We have not been deterred by the strictures of isolation, lockdown, zoom, or even inadvisable government edicts as we continue our work in this space. And we are becoming more and more innovative in our methods of collecting our data and disseminating it. This is a natural and good development and something we should pursue to ensure our relevance and presence in the international field.

This year's Newsletter highlights our achievements over the last twelve months. As usual, it's a varied, informative and interesting read. I hope you enjoy it. I look forward to catching up with you at our next meeting in November, and I hold great hopes for a face-to-face meeting next year.

Happy reading!

With my best wishes to you all,

Lorraine Smith

DIPEX International Chair



Australia

University of Sydney team activities

This year the Sydney team have been working on publishing a series of Podcasts on patient experiences of severe asthma. Three episodes were scripted, drawing on the Talking Points appearing in the Severe Asthma Healthtalk Australia module. The episodes cover how severe asthma affects home, family, relationships, social life and work, mental health, interactions with health professionals, and advice and messages. We expect to have these finalised by the end of October and published on the Healthtalk Australia website and made available to a range of stakeholders including consumer organisations, universities, and clinicians.

RMIT University team activities

Reproductive health project

Experiences of Infertility and Fertility Treatment (2020-21)

The Experiences of Infertility and Fertility Treatment project, part of a 5-year \$2.5 million Centre for Research Excellence in Women's Health in Reproductive Life funded by the National Medical and Health Research Council (NHMRC), is nearly complete. We conducted online interviews with 25 women and gender diverse people presumed female at birth about their experiences of infertility and fertility treatment and are now writing up the content for the online resource, to be completed by the end of November 2021.

Mental health projects

Borderline Personality Disorder as Social Phenomenon (2021- 24)

Data collection is now underway for the Borderline Personality as Social Phenomena project, which is a three-year AUD \$1 million project funded by the Australian Research Council Linkage Project scheme and partner organisations, including National Mental Health Commission, Mental Health Victoria, Mind Australia and Victorian Department of Health.

We have also welcomed on board three new project members, Emma Seal (Research Fellow), Tamara Borovica (Research Associate), and Lucy Brown (Project Manager) to help execute the research.

We are collecting data via a national survey that allows people to upload a creative work(s) that represents their lived experience, through a series of arts-based workshops, and a set of narrative interviews that will include people with lived experience of Borderline Personality, and also health practitioners. The survey closed at the end of September 2021 and has elicited a range of exciting creative works including narrative accounts, poems, drawings, photographs, and songs. The arts-based workshops have also progressed well despite COVID-19 lockdowns in Melbourne and we have now facilitated one face-to-face and two online workshops. These are due to be completed in December 2021 and have also fostered a rich array of creative outputs. We are commencing the narrative interviews online in October with the aim of completing these by mid-2022.

Closing the Mental Health Care Gap: Co-Designing Resources for Emergency Department Staff

This project received internal RMIT University funding (\$130,000) and aimed to develop mental health education and training resources to support emergency department staff providing mental health care. The research has been conducted in partnership with the Australasian College of Emergency Medicine (ACEM), Mind Australia, and St Vincent's Hospital. We conducted 17 interviews with people who presented to ED with mental health concerns and 18 health practitioners located within EDs, including clinicians, emergency care nurses, consulting psychiatric registrars and peer workers. The first phase of the project has involved the production of a series of 18 animations based on lived experience audio recordings which have been produced in collaboration with peer researchers. These animations will form the basis of the Mental Health Care in the Emergency Department: Learning from Lived Experience online resource hosted on the Healthtalk Australia website.

The RMIT based team has received further funding (\$98,000) from ACEM to develop mental health education and training resources to support people working in regional and rural EDs based on the interviews we conducted with ED staff, to be made available in the form of a podcast.

Physical Health Experiences of People who have Accessed Mental Health Services (2020-22)

The Physical Health Experiences of People who have Accessed Mental Health Services project is a partnership between researchers from RMIT University, Charles Sturt University, Equally Well initiative and Healthtalk Australia, guided by a multi-disciplinary Project Advisory Group and a Lived Experience Leadership Advisory Group. The project aims to address significant knowledge gaps regarding the coexistence of psychiatric service use and physical health conditions through collecting narrative accounts of these experiences. Funding for the project (\$250,000) was provided by the National Mental Health Commission, the Victorian Department of Health, and the New South Wales (NSW) Mental Health Commission. Thirty interviews across Victoria and NSW will be conducted. To date, the project team has conducted 16 interviews and aims to complete the remainder over the next several months. The online resource will be available in late 2022.

Joint activities between Sydney and RMIT Universities

DIPEX International Experiences of COVID-19 pilot study (2021-21)

Our joint collaboration with our international colleagues on experiences of COVID-19 has progressed this year. In Australia we have interviewed eight people who have had the coronavirus, and we have coded the interview transcripts using the coding framework agreed upon during our regular international COVID research meetings. We have just commenced the development of seven short films on key aspects of the 'COVID journey', including both acute and long-COVID experiences: (i) Physical experiences; (ii) Experiences of medical care and navigating the health system (e.g., seeking help, testing, diagnosis, treatment, experiences with health practitioners);

(iii) Emotional and mental health impacts; (iv) Social and relationship impacts with family, friends and wider social network; (v) Impact on lifestyle (e.g., daily activities, work, hobbies / interests); (vi) Recovery and thoughts about the future; and (vii) Advice to others (people who have experienced COVID, health practitioners, the general community). We hope to have these ready by the end of the year. We look forward to our continued collaboration internationally on this.

Welcoming New Healthtalk Australia Coordinator

We are very pleased to announce that Lucy Brown has joined us as our new Healthtalk Australia Coordinator. Lucy is the Project Manager for the ARC LP Borderline Personality Disorder as Social Phenomena, led by Renata Kokanovic. She brings her experience in both qualitative and quantitative social research and project management, with a particular focus within the public health and disability sectors. Lucy's research management experience includes multiple projects exploring both consumer and carer experiences of publicly funded health services, including mental health services across Australia. We look forward to working with Lucy!

Warm regards to all DI colleagues from the Healthtalk Australia team. Renata, Kate, Lorraine, and Lucy.

Conferences and presentations

Johnston-Ataata K. (2021) Women's experiences of early menopause & premature ageing. My Menopause panel, Flesh After Fifty Exhibition. Melbourne, Australia, March.

Book chapters

Eassey, D., **Smith, L.**, Ryan, K., & Davis, S. Medicines use for severe asthma: people's perspectives. In Ballantyne, P.J., & Ryan, K. (2021). *Living Pharmaceutical Lives*, Routledge, Oxford, UK.

Journal articles

Eassey, D., Reddel, H. K., Ryan, K., & **Smith, L.** (2020) 'It is like learning how to live all over again' A systematic review of people's experiences of living with a chronic illness from a self-determination theory perspective, *Health Psychology and Behavioral Medicine*, 8:1, 270-291, DOI: 10.1080/21642850.2020.1794879

Eassey, D., Reddel, H. K., Ryan, K., & **Smith, L.** (2021). Barriers to belonging: the need for relatedness amongst people living with severe asthma. *Journal of Asthma*, Jan; 58(1):1-9. DOI: 10.1080/02770903.2019.1656230

Johnston-Ataata K, Flore J & Kokanović R. (2020) Women's Experiences of Diagnosis and Treatment of Early Menopause and Premature Ovarian Insufficiency: A Qualitative Study. *Seminars in Reproductive Medicine*. 38(04-05): 247-255. DOI: 10.1055/s-0040-1721463

Yeganeh, L., **Johnston-Ataata, K.**, Vincent, A., **Flore, J.**, **Kokanović, R.**, Teede, H., & Boyle, J. A. (2020). Co-designing an Early Menopause Digital Resource: Model for Interdisciplinary Knowledge Translation. *Seminars in Reproductive Medicine*, 38(04-05), 315-322. DOI: 10.1055/s-0041-1726273

Brazil

The first module – Leprosy will be launched next November 2021

At all 43 interviewees accepted to participate on leprosy module – 24 interviews were conducted in Porto Velho, capital of Northwestern province of Rondonia, and 19 in Rio de Janeiro capital in Southeast region. All of interviews were conducted in the regional referral centres for the Northwestern Amazonian region, and Rio de Janeiro city, peripheral area respectively, where leprosy is endemic.

The thematic analysis has been discussed by Alicia and her two “buddies” Marcelo Castellanos and Nelson Filice.

The summaries of the themes and sub-themes have been discussed by Octavio Serpa and Jose Ricardo Ayres. At the end the Advisory Board gave us feedback.

The COVID-19 project

Many members of DIPEX Brasil team got interested in developing the research on COVID-19 illness and care experiences. We wrote a project named COVID NARRARE to involve participants as persons who suffered the coronavirus infection; relatives' experiences; and the health professionals' experiences who work at the front line at primary or tertiary care. In June 2020, this project was approved at UFRJ's Faculty of Medicine Ethical Board. We also applied for funding, but we were not successful. However, we began doing interviews mainly through Zoom platform. We conducted at all 53 interviews – 26 in 2020 and 27 in 2021 – with such participants: COVID patients who needed hospitalization most of the times at ICU in public or private health system; COVID patients who did not need hospitalization and were treated as outpatients in public or private health system; and health professionals' who work at the front line at primary or tertiary care, most of them was infected by COVID.

Timeline of COVID in Brazil since its outburst

The DIPEX Brazil team was also committed to tracing the timeline of COVID in Brazil. Information has been collected in scientific databases and in vehicles for the dissemination of campaigns by the Ministry of Health, local government actions and other initiatives by non-governmental entities, to understand the direction that the health crisis has taken in our country. The study has been completed, and it will be submitted soon to a Journal. The task has been led by Ivone Cabral and Antonio Cyrino.

PhD students

Daniela Bastos and Juliano Luna will present on next Conference their research named “Facing Perinatal Loss: The experience of mothers, fathers, and health professionals”;

and “*The Heart and Its Reasons: Illness experience among heart transplant patients*”, respectively.

The “Diversity, Equity and Inclusion” DI working group

Many members of DIPEX Brasil team got interested in participating on this working group and they will present their ideas on next Conference, November 2021.

Canada

The Canadian health experiences research team is happy to report a busy and productive year thanks to some excellent collaborations, a bit of luck with grants, and an inspiring team!

Current projects

Women's experiences of heart failure - NEW project

In partnership with patient-led groups for heart failure, we have received a 3-year grant from the Canadian Institutes of Health Research (our national funder) to create an online module about the lived experiences of women with heart failure. As women are known to be under-diagnosed, under-treated and under-represented in cardiovascular research, our aim is to provide practical support for those living with this condition and for those that care for them. Title: *From the heart: Canadian women's lived experiences of heart failure*. We have just received ethics approval and will start data collection soon.

Experiences of long-COVID – NEW project

We received a second CIHR grant this year to create a collection of narratives on experiences of long-COVID. We are delighted to work with two pan-Canadian long-COVID support groups and decision maker partners over the next year to gather stories across Canada and create new online resources. Title: *Living with long-COVID. Patient experience to inform policy makers and care providers*. We are working on ethics approval now and will start data collection soon.

USydney-UToronto Collaboration Award on medical cannabis – IN PROGRESS

Pre-COVID, the USydney team (Lorraine, Daniella and colleagues in Pharmacy) together with our Canadian team embarked on a small comparative study on the policy context related to the use of medical cannabis for chronic pain. This has involved data collection in each country including a media and policy document review, qualitative interviews with about 15 people involved in decision-making, advocacy and/or delivery. We have completed these phases and are now hosting focus groups to help articulate advice related to directions for policy and practice in each country.

Experiences of COVID-19 Pilot – COMPLETED

Our team undertook a small number of interviews with 15 people who had COVID-19 in the first or second wave. This sample was limited in many ways but yielded helpful insights for our long-COVID study, and we are currently preparing a manuscript for publication based on these results. We are also delighted to contribute whatever findings and analysis may be useful to the DIPEX International efforts to bring the findings of COVID experiences projects from individual countries together.

Perinatal Mental Health – extension for full module – RE-BOOTED

Our team, in collaboration with patients as well as clinical colleagues at St. Mary's Research Centre, has re-opened the perinatal mental health project to extend data collection for a full module. We will collect an additional 20-30 interviews in Ontario, Quebec, and Nova Scotia to add to our existing pilot data.

Grants submitted

We submitted two grants this Spring/Summer – one to the Canadian Cancer Society to assess how women with breast cancer seek and access information over the course of their illness and care, focusing on the particular value of evidence related to others' experiences. Title: *How to know what to know: addressing the information challenge for women with breast cancer*.

The second is an international study, led out of Stanford University (USA) regarding the role of long-COVID support groups in mobilizing knowledge for patient care – involving USA, Canada, UK, and Brazil. Title: *Co-producing Long COVID knowledge to improve health system responsiveness: learning from the mobilization and engagement of people with lived experience*. This will involve gathering experiences of advocacy as well as institutional and clinical change over time. Notices of results are expected in January for both grants.

New team members

Our core team has grown and we have been delighted to welcome: **Emily Gard Marshall**, PhD, associate professor in family medicine at Dalhousie University in Nova Scotia, who will help to coordinate engagement and research in the Atlantic region of Canada; **Cathie Scott**, PhD, a knowledge translation consultant and adjunct associate professor at the University of Calgary in Alberta, who will help to coordinate engagement and research in Western Canada; patient and caregiver partners **Marc Saint-Cyr** (Montreal), **Linda Tracey** (Montreal), and **Patricia Pottie** (Ottawa), members of our core patient advisory group who have contributed to several consultations to date; **Ana Paula Keller de Matos**, PhD, our new Research Assistant based in Montreal, a qualitative researcher who recently completed her PhD in San Paulo and moved to Canada from Brazil; **Caitlin Goodman**, MMASc, our new social media lead and former summer student, who recently completed her master's at the University of Western in applied health sciences with a focus on global health systems; **Ryan Caulfeild** has been a summer student for two years (undergrad in business at McMaster University) and has now joined us part-time to provide tech support and video editing wizardry; and, we are delighted that **Linda Rozmovits**, DPhil, who worked with the original DIPEX team in Oxford and more recently with our US colleagues, has joined our team as a senior qualitative researcher to support our long-COVID study and other initiatives.

Social media strategy - NEW!

With thanks to our new team member, Caitlin Goodman, we now have a social media strategy and initial engagement with Instagram and YouTube using existing material from our web site and published information. We held a preliminary planning session with patient partners to ask how to start incorporating material from the module on social media platforms, and what they thought we should do to ensure participants' comfort in doing so. Based on their advice, we are writing to all former participants to ask for feedback and to note their preferences for disseminating clips and information related to their narratives on social media; original consent for earlier studies would not have included the possibility of social media as a mechanism for sharing results more broadly. See us at [healthexperiencescanada](#) on Instagram and at our YouTube channel!

Teaching/presentations

- Special Seminar for national Knowledge Translation Research Network graduate trainees in knowledge translation on health experiences and patient engagement – presentation of our patient-researcher partnerships module. MMarcinow/SLaw/PPottie – March 12, 2021, University of Ottawa.
- Launch of inaugural course at the University of Toronto Dalla Lana School of Public Health on Patient Engagement in Research (Spring 2021 term) – led by KKuluski, SLaw on course organizing committee; presentation in-class on health experiences and engagement work including IOrmel, MMarcinow, SMahmood, LTracey, May 31, 2021.

Special achievement

- Congratulations to Ilja for successfully defending her PhD on October 6th, 2021!! With thanks also to Lisa Hinton who participated as a member of her thesis committee. Ilja has now started a postdoctoral fellowship in humanitarian aid and global health based at McMaster University. We are very grateful that she will continue part-time with our health experiences team.

Publications

- Cassidy, C. E., Beck, A. J., Conway, A., Varin, M. D., Laur, C., Lewis, K. B., Ramage, E. R., Nguyen, T., Steinwender, S., Ormel, I., Stratton, L., & Shin, H. D. (2021). Using an integrated knowledge translation or other research partnership approach in trainee-led research: A scoping review protocol. *BMJ Open*, 11(5), e043756. <https://doi.org/10.1136/bmjopen-2020-043756>
- Ormel, I., Onu, C. C., Magalhaes, M., Tang, T., Hughes, J. B., & Law, S. (2021). Using a Mobile App–Based Video Recommender System of Patient Narratives to Prepare Women for Breast Cancer Surgery: Development and Usability Study Informed by Qualitative Data. *JMIR Form Res*, 5(6), e22970. doi:10.2196/22970
- Cadel L, Marcinow M, Sandercock J, Dowdoff P, Guilcher SJT, Maybee A, Law S, Kuluski K. A scoping review of patient engagement activities during COVID-19: More consultation than partnership. *PLoS ONE* 16(9): e0257880. <https://doi.org/10.1371/journal.pone.0257880>
- **Mahmood S**, Bombard Y, Law S. ‘I have to start learning how to live with becoming sick’: A scoping review of the lived experiences of people with Huntington’s Disease. *Clinical Genetics*, July 3, 2021. <https://doi.org/10.1111/cge.14024>
- Law S, **Ormel I**, **Babinski S**, Kuluski K, Quesnel-Vallée A. “Caregiving is like on-the-job training but nobody has the manual”: What caregivers say about their roles within the healthcare system. *BMC Geriatrics* 2021, 21(404), 1-11. <https://rdcu.be/cnwQA>. <https://doi.org/10.1186/s12877-021-02354-z>
- **Dimmer A**, Rozmovits L, Babinski S, Law S. Mental illness in the family: the experiences of well siblings of young adults with mood and anxiety disorders. *Accepted for publication in the Canadian Journal of Community Mental Health*, June 10, 2021.
- Rajabiyazdi F, Alam R, Pal A, Montanez J, Law S, Pecorelli N, Watanabe W, Chiavegato L, Faconi M, Hirano S, Mayo N, Lee L, Feldman L, Fiore J. Understanding the meaning of recovery to patients undergoing abdominal surgery. *JAMA Surgery*, May 12, 2021. doi:10.1001/jamasurg.2021.1557. Published online: <https://jamanetwork.com/journals/jamasurgery/article-abstract/2779967>
- Law S, Ormel I, Babinski S, **Plett D**, Dionne E, Schwartz H, Rozmovits L. Dread and solace: talking about perinatal mental health. *International Journal of Mental Health Nursing* 2021; 30(S1): 1376-1385. *First published May 24, 2021*. <https://doi.org/10.1111/inm.12884>
- **Ormel I**, **Onu C**, Tang T, Magalhaes M, Hughes JB, Law S. Using a mobile app–based video recommender system of patient narratives to prepare women for breast cancer surgery: development and usability study informed by qualitative data. *JMIR Formative Research*, June 2, 2021. <https://formative.jmir.org/> and <http://dx.doi.org/10.2196/22970>
- **Ormel I**, Salsberg J, Hunt M, Doucet A, Hinton L, Macaulay A, Law S. Key issues for participatory research in the design and implementation of humanitarian assistance: a scoping review. *Global Health Action* 2020; 13(1): 1826730, DOI: 10.1080/16549716.2020.1826730. <https://doi.org/10.1080/16549716.2020.1826730>
- Schwartz H, McCusker J, Law S, Zelkowitz P, Somera J, Dyachenko A, Singh S. Perinatal mental healthcare needs among women at a community hospital. *Journal of Obstetrics & Gynaecology Canada* 2021; 43(3): 322-328.e1. Pre-publication online September 8, 2020 at: <https://doi.org/10.1016/j.jogc.2020.08.015>. <https://authors.elsevier.com/c/1cOef62pzATJw8>
- **Ormel I**, Magalhaes M, Josephson D, Tracey L, Law S. How to know what to know: information challenges for women in the diagnosis phase of breast cancer. *Patient Education and Counselling* 2021; 104(1): 179-185. <https://doi.org/10.1016/j.pec.2020.06.030> and <https://www.sciencedirect.com/science/article/abs/pii/S0738399120303487>

Czech Republic

The Czech DIPEX team successfully finished new modules in 2021. These modules were created in cooperation with our Ph.D. candidates.

Current activities

We are excited to announce that we published two new modules on the website.

Firstly, Hearing Impairment in children, which was published in February 2021. The module is reflecting lived experience of parents of children with hearing impairment and their challenges. We are proud that this module has its simultaneous translation into sing language and Czech subtitles. We see this as a unique adaption to the needs of the target group.

Secondly, the Lyme disease module was published in June 2021. The press conference was held on the 29th of June (picture attached). The published module had national media attention – the article was published in national paper and on online newspaper.

Currently, we have been working on the final version of our module on ADHD, which is going to be launched on our website by the end of 2021. Also, the module on nightmares is in its final rounds of preparation. We are also working on a module on Autism. A new module, which we have been preparing is perinatal mental problems in mothers.

We are using the DIPEX methodology to make unique movies of living experiences. We are filming COVID experiences of people. We are looking into experiences of health care workers, parents, people who lost someone and people who trust conspiracy theories. We have collected DIPEX data on experiences of people with haemophilia. Due to limited funds we were not able to publish the module on the website. However, we created movie based on this data. Lastly, we have published short movie on breaking down the prejudice, which had high impact on social media (it was seen by over 500k people).

Grant applications

We applied for several funds in 2021. Among others, we applied for Horizon “Sharing and reuse” program. We are still waiting for the application results.

Publications

Published

Černíková, K. A., Klůzová Kračmarová, L., Pešoutovová, M. a Tavel, P. (2021). Odkládání návštěvy lékaře při podezření na karcinom prsu u žen v České republice. [Patient delay in presenting symptoms of breast cancer in women in the Czech Republic.]. *Klin Onkol* 34(1), 40-48. DOI: 10.48095/ccko202140.

Horáková, R., Gábová, K., Tavel, P. (2020). Diagnostic process and subsequent care of children with early-age hearing impairment: Parents’ experience, *Listy klinické logopedie*, 4(2), 84-91. doi: 10.36833/lkl.2020.037

Lamerichs J., Andreassen H.K., Klůzová Kráčmarová L., Alma M. (2021) Fostering “Digital Subjectivity”: An Investigation of Digital Health Narratives in Norway, the Netherlands and Czechia. In: Svalastog A.L., Gajović S., Webster A. (eds), *Navigating Digital Health Landscapes. Health, Technology and Society*. Palgrave Macmillan, Singapore. https://doi.org/10.1007/978-981-15-8206-6_6

Accepted

Trtílková, J., Klůzová Kráčmarová L., Horák, O., Tavel, P. (2020). Zkušenosti rodičů s poskytovanou zdravotní péčí o děti s epilepsií [Experiences of parents with health care provided to children with epilepsy.]. *Neurologie pro praxi [Neurology for Practice]*.

Navrátilová, V., Weigl, E., Černíková, K. A., Meier, Z., Tavel, P. (2021). Lymeská borrelióza z pohledu pacientů – kvalitativní studie. [Experiences of patients with Lyme disease – qualitative study.]. *Neurologie pro praxi [Medicine for Practice]*.

Submitted

Krtkova, R., Krtek, A., Malinakova, K., Tavel, P., (2021). Tragicomedy of ADHD as a source of positive coping strategies of parents. The Research of developmental disabilities.

Krtkova, R., Krtek, A., Malinakova, K., Pesoutova, M., Tavel, P., (2021). Ambivalent bonds, positive and negative emotions, and expectations in teachers' perceptions of relationship with their students with ADHD. International Journal of Qualitative Studies in Health and well-being.

Krtkova, R., Krtek, A., Malinakova, K., Pesoutova, M., Tavel, P., (2021). What influences do parents perceive as supportive for school well-being and inclusion of their children with ADHD?: A qualitative study, European Journal of Special Needs Education.

Project promotion and conferences

Conference: Disease as a diagnosis and/ or part of the lifespan. Olomouc, 15th September. The contribution was held by Mgr. Lenka Slepíčková, Ph.D. with title: *The way to the diagnosis: the experience of the families with children with autism.*

Our team continues to promote the DIPEX project throughout the Czech Republic. We participate in radio broadcasting, magazines, and other important events, whether by a short presentation of the project or by a distribution of leaflets and displaying of banners.

Germany

Team

The team of DIPEX Germany of Christine Holmberg (project manager), Martina Breuning (scientific supervision), Anne Thier (coordination) and Lea Minow (research assistant).

Website

The website is now located at the Institute for Social Medicine and Epidemiology at the Brandenburg Medical School. In the course of the move, however, the module 'Chronic Pain' had to be significantly reduced for data protection reasons. It will be updated as soon as possible.

Last year we received a donation of the Krebsallianz (Cancer Alliance) foundation in order to strengthen and maintain the infrastructure of the database and website project and to further develop the platform. This donation helps to secure the project for 2 years.

At present, the website is being successively revised, updated and optimized. A solid infrastructure is being built up to ensure the long-term maintenance of krankheitserfahrungen.de. The site is made clearer and more accessible in terms of content and design in accordance with the latest findings and media options. In addition to the background texts ('About Us'), all further information and links were updated, gender-appropriate language was established, superfluous information was removed, content was restructured, etc. Other tasks such as adapting the accessibility of the site to the latest technical requirements and other changes to the content are currently worked on.

As part of the public relations work, the website was once again presented to the public on the Institute's Twitter account with small excerpts from the areas of experience, which led to an increase in visits to the website.

Furthermore, DIPEX Germany is currently working on expanding the website to include a research section. Here, an overview of scientific publications that have already been published within the framework of krankheitserfahrungen.de will be created, as well as an overview of further research possibilities with the DIPEX Germany database, e.g. in the form of secondary data analyses.

New projects

We applied for a funding for a module about COVID-19 that was approved in July 2021. A pilot version of the Covid-19 module will be launched on November 10th and we are currently exploring how to do this in a scientifically rigorous way. The final version is planned to be published in July 2022.

Publications

Schulze M, Breuning M, Holmberg C, Müller-Nordhorn J. The Evaluation of a Health Website Presenting Real User (Patients') Experiences. 2021 (forthcoming).

Holmberg C, Breuning M. Personal Experience of Illness. In: Scrimshaw SC, Lane SD, Rubinstein RA, Fisher J, editors. Sage Handbook of Social Studies in Health and Medicine 2021 (forthcoming).

Kaiser M, Adami S, Lucius-Hoene G, Müller-Nordhorn J, Goerling U, Breuning M, et al. Learning-by-doing: the importance of experiential knowledge sharing for meeting the information needs of people with colorectal cancer in Germany—a qualitative study. *BMJ Open*. 2021;11(2):e038460.

Blödt S, Müller-Nordhorn J, Seifert G, Holmberg C. Trust, medical expertise and humaneness: A qualitative study on people with cancer' satisfaction with medical care. *Health Expect*. 2021;24(2):317-26.

Our homepage now has a new design, 9 red circles are modules already online, and 3 white circles are modules that are under way.

Website launch

We launched **the Students with Disabilities module** in January 2021. This module was led by Yoko Setoyama, who herself became disabled when she was an undergrad. Current website contains 33 interviews with students and former students of higher education with a broad range of disabilities, including impairment of vision, hearing and speech, orthopedic impairments, developmental impairments, chronic illness and other health conditions. 4 more interviews are soon to be added.

The module is aimed to provide information to young people with disabilities who are seeking to enter higher education, and good examples to the administrative staff as well as the teaching staff in academic institutions on how to accommodate the needs of students with disabilities.

We are also collaborating with the Inclusive Academia Project at University of Tokyo to collect interviews of researchers with disabilities in the field of science, technology, engineering, mathematics, and medicine (STEMM) to find out the current conditions of inclusivity in those research fields. We have conducted 12 interviews with Japanese researchers and are now planning to interview researchers overseas as well.

Another website we launched this year is **the pilot version of the COVID-19 module**. The project is led by Rika Sakuma Sato. We began recruiting in October 2020, and conducted 10 interviews by March 2021. Initially, we had planned to collect 35-50 interviews as our usual modules, but the research staff as well as the advisory board members felt the urgent societal need for experience-based information from COVID-19 patients and their families, and decided to launch a pilot version of the module with initial 10 interviews.

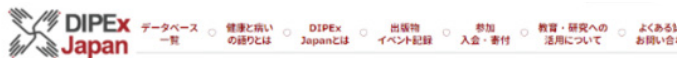
Japan



The major concern in publishing the findings was that they were based on research with a small-size sample. While we tried to collect experiences of both sexes and different ages, varying family structure, different degrees of symptom severity, etc., we could not secure an ideal maximum variation for our interview sample. Thus, we chose the 7 topics (with roughly 60 clips) which we felt comfortable or safe to present to the public at this point.

This was the major reason we did not include experiences of medical treatments and hospitalization in the pilot version.

Another prominent difference from other modules is that interviewees are more cautious in making their experience public. Only half of the interviewees agreed to show their video clips on the website, while more than 80% of the interviewees in the breast cancer and prostate cancer modules had their video clips published on the web. Moreover, people tended to cut out far greater portion of their transcripts than the interviewees of other modules, because they were worried that what they had spoken in the interview might have a negative impact on others who were referred in their story. It was not just the blatant social stigma placed on the epidemic that concerned our interviewees. It seems that the experience of corona infection revealed the preexisting structure of power or inequality, and uncovered the difference in life values held by people around them.



私になるわけがないという気持ちがあった。可能な限り在宅勤務していたし、通勤ラッシュや人込みは避けるようにして、マスクもしていたので、感染経路が全くわからない

※写真をクリックすると、動画の再生が始まります。

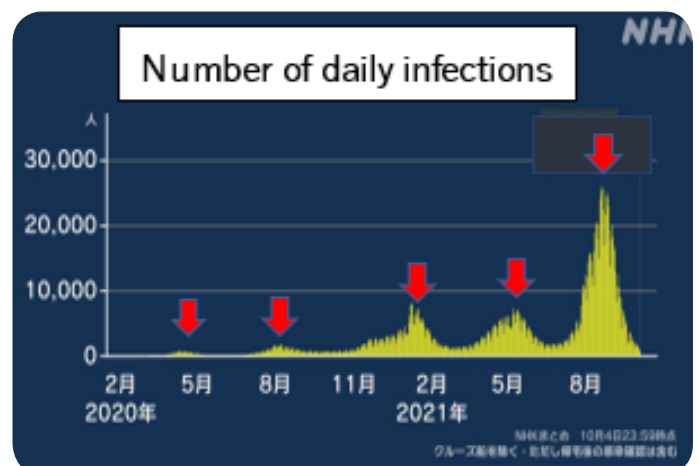


プロフィール
インタビュー01
インタビュー時年齢：38歳（2021年1月）
感染時期：2020年3月
背景：首都圏在住の女性。新進記者。夫と長男（当時3歳）と次男（1歳）の子ども4人暮らし。勤務先の新進社で仕事中に感染陽性に気づいた。PCR検査を希望したものの発熱がなかったため受けられず、発症から4日目によりやく検査を受け陽性だとわかり、入院できたのは10日目だった。入院後もまもなく軽症ということで退院

1. Possible route of infection
2. Early signs
3. Symptoms during acute phase
4. Patients' anxiety and distress
5. Impacts on job and workplace
6. Young children and infection
7. Perspectives of life and world after infection

There are striking differences between the experiences of COVID-19 and those of other chronic illnesses including cancer. For one thing, the COVID-19 experiences are heavily time and place dependent. The experience of those who were infected during the early months (Spring 2020) of the pandemic is quite different from those who got ill in the Summer of 2021. This was one of our concerns in publishing the results on the Internet in early September, as we only had data on the experience of infection during the year 2020 when the healthcare system was still functioning. We were worried that some of those experiences might appear irrelevant to those who got infected during the 5th wave (peaked in late August 2021), because at the time due to the lack of hospital beds, over 130,000 patients including those who had pneumonia had to fight the disease at home without receiving any medical care.

All 10 interviews in the pilot module were conducted remotely, using either Zoom, LINE, or a telephone. Since April, we have collected 4 more interviews including one face-to-face interview conducted early summer, when the government declaration of the “state of emergency” was temporarily lifted. Since we secured a funding to collect 40-50 interviews in total, we are continuing to collect interviews to launch a full-scale module in Spring 2022.



Other ongoing projects

We are also working on **the Families of Children Requiring Long-term Medical Care module**. The project team led by Kyoko Kobayashi and Ryoko Hatanaka has so far collected over 30 interviews of mostly mothers caring a child who need constant medical care, such as artificial ventilation, phlegm suction, and gastrostomy.

More than 30 interviews have been collected by Noriko Iba for **the Heart Failure module**, and 5 interviews by Natsuko Takahashi for **the Type-II Diabetes module**. Most of these interviews were collected online, but we feel that we need to resume face-to-face interviews as well, in order to collect experiences of elderly, or economically disadvantaged patients. Since most of our researchers have already had their second vaccination, we feel more comfortable about meeting interviewees in person. To reduce the risk of the breakthrough infection, the interviewer must prove PCR negative within 72 hours before the face-to-face interview.

Knowledge translation and dissemination

There has been a continuing interest among the educators in the field of health science for the DIPEX-Japan website. While it is free to use the clips on our website in lectures and workshops, we also provide a series of catalyst films and lecture slides to the paid subscribers of our website.

We also allow, after a careful examination of application forms, researchers from other institutions to use our interview data with a small fee. Data sharing, as we call it, has produced a number of papers in peer-reviewed journals (unfortunately most of them in Japanese) and is considered by many experienced researchers as a reliable resource of illness narratives in the age of Pandemic, when it is so difficult to conduct interviews. Both qualitative and quantitative researchers have been using our data. We also provide the data to graduate students and undergrads who are writing a thesis for their academic degree for a smaller fee. Currently, we are sharing our data with 10 researchers and 5 students.

Events and meetings

Before the Pandemic, we used to hold many fundraising events, which were also “fun” events, such as hiking out to dig up bamboo shoots, craft beer tasting, and a miso-paste workshop. Unfortunately, during the past 22 months, we had no such events. No fun.

Even our monthly organizational meetings take place online and we haven’t met each other in person for a long time. But there has been a bright side to this online workstyle. Before the Pandemic, the active members were concentrated in the Tokyo metropolitan area, but now we have young researchers from different parts of Japan joining the team and receiving training sessions online.

Similarly, while we miss the face-to-face interactions and big hugs from our DI colleagues, we also appreciate the ease of getting in touch with each other on Zoom in spite of the physical distance that separates us. Obviously, having two meetings within a year is something we could never imagine before. I am sure that the bonds between the DI members will get even stronger through the collaborations on COVID-19 study.

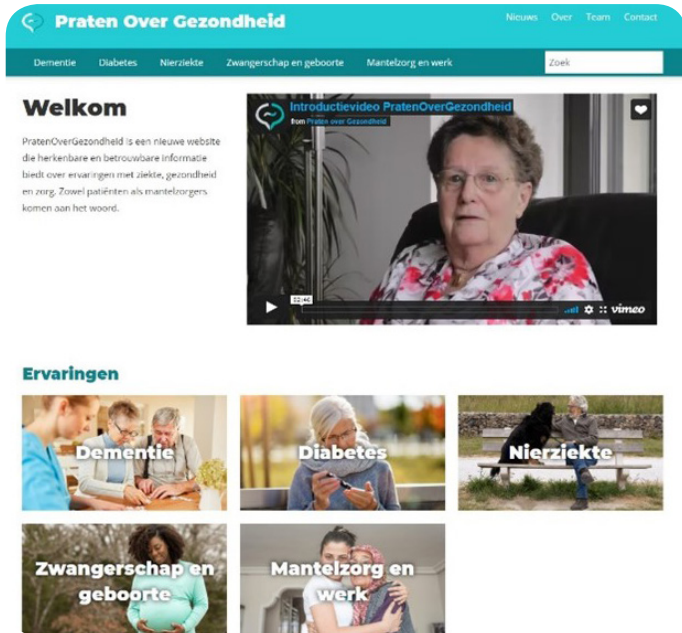
So, let’s work together to make 2022 a fruitful year for the DIPEX International!

Rika from DIPEX-Japan

Netherlands

Dutch website is renewed!

Eight years ago, we launched our first module. The outdated look and some technical issues led to the renewed website www.pratenovergezondheid.nl. Thanks a lot to Adam Barnett and Jo Kidd for their collaboration and support!



Project: Stories of adults diagnosed with psychotic spectrum disorders on social (re)integration: development of two experienced-based interventions

We started working on a new module on psychosis in spring 2021. This project focuses on stories of adults with a psychotic spectrum disorder in order to better understand their experiences and learn how these experiences can contribute to improving care. In this study, we will investigate the stories of adults with a psychotic spectrum disorder in different ways. Firstly, we do this by analyzing written stories from a collection of experience stories. We also conduct videotaped interviews with patients based on the analysis of the written stories. The insights from the stories are translated into two interventions aimed at improving the social (re) integration of people with a psychotic disorder. Both interventions make use of the videos created and are implemented, evaluated and disseminated throughout the project. One of the interventions is a module for the Dutch Dipex website, www.pratenovergezondheid.nl. The project will run for four years and is funded by the Dutch National Organization of Scientific Research. In this project, Andrea and Manna will collaborate with Joyce Lamerichs (VU) and Hester van de Bovenkamp and Marjolijn Heerings (Erasmus University).

In February 2021, we had an online kick off meeting with the project team. Everybody was very excited to start. We first started analyzing written patient stories. These stories offer in-depth information on patient experiences and the opportunity to do justice to diversity by comparing different stories. We analyze these stories focusing on experiences with and preferences regarding living conditions and spending leisure time and the influence of stigma, but also pay attention to how these relate to peoples' broader experiences with living with psychotic spectrum disorders.

Later this year, we will start with preparations for the video-recorded interviews planned for 2022.

New project: Persistent symptoms after COVID-19 (Long COVID) from the perspective of the population, patient and health care

After recovery from the acute symptoms of COVID-19, a substantial proportion of people experience persistent symptoms of physical, psychological and cognitive nature: Long COVID. It is unclear what the causes and consequences of these complaints are for the individual and for society, and how healthcare can respond to them. Our study aims to generate practically applicable knowledge for improving care for patients with Long COVID. Specially, we will map the prevalence, characteristics and personal and social consequences of these symptoms in a multidisciplinary study. Our Dutch Dipex team is responsible for a qualitative study in which 25 patients will be interviewed about the impact of Long COVID on their daily lives and their experiences with recovery and aftercare and self-management leading to an online module with patient experiences. At the same time, other researchers from our University Medical Center are using a large Northern-Netherlands database to search for specific pathophysiological mechanisms and multidisciplinary risk factors for Long COVID-19 and to map the consequences of Long COVID-19 on quality of life and healthcare costs, absenteeism and production loss costs.



In about a year, the results of the different sub studies come together in an action research in which care providers develop a multidisciplinary care path together with patients and other national initiatives. Our team is leading this action research. We will organize several working conferences to implement this care path, to learn from the experiences with it and from the results from the other parts of the research in order to continuously improve this care path in terms of content and organization. Nienke, Jeanet, Andrea and Manna are involved in this project. We collaborate with Radboud UMC Nijmegen, other partners such as the patient association Lung Fund. The project is funded by ZonMW.

New project: Stories about monthly periods

About 30-50% of all menstruating women find their periods (very) heavy. In collaboration with Maastricht University and Maxima Medical Center, we will collect experiences about monthly periods and analyze these according to the DIPEX methodology leading to a new module for the PratenOverGezondheid website. This project will start in the beginning of 2022. A junior researcher will be appointed supervised by Manna.

Publications

Landsman, J. A., Verheij, N. P., Alma, M. A., van den Boogaard, J., Luning-Koster, M., Evenboer, K. E., van der Mei, S. F., & Reijneveld, S. A. (2020). [Covid-19: recovering at home is not easy]. *Nederlands Tijdschrift voor Geneeskunde*, 164, [d5358]. *In Dutch*.

Lamerichs J, Andreassen HK, Klůzová Kráčmarová L, Alma M. Fostering “Digital Subjectivity”: An Investigation of Digital Health Narratives in Norway, the Netherlands and Czechia. Chapter in Svalastog AL, Gajović S, Webster A. *Navigating Digital Health Landscapes*. 2021: Palgrave MacMillan. Pp107-126.

Norway

New Member!

This year we are happy to introduce a new member to the Norwegian Dipex team: Sigrid Gabrielsen!

Sigrid is a PHD student and will do her project on the experiences of persons receiving digital speech and language therapy. She only started this semester and is still in the process of writing up the detailed project protocol. Interviews will start during 2022. We are so lucky to have Sigrid on board!



Our new member - PhD student Sigrid Gabrielsen with Hege and Marianne

Ongoing activity

During 2021 we have presented the project and our work in local and national meetings and conferences on several occasions, always aiming to expand the network and foster new collaborations across the country, and across different empirical contexts.

We also participated in several applications for national and international funding – all had good rating from scientific committees, but unfortunately, only one made it through the last and crucial step. This is the project Sigrid will work on! Now we look ahead towards 2022, where we aim to provide a solid base for our new project as well as the ongoing ones, have a strong focus on recruitment, and of course on building networks within Norway – and perhaps also with other Scandinavian countries! Stay tuned...

Knowledge translation and dissemination

We have developed a website linked to DIPEX Spain called MUSA experience, available at: <https://www.musaexperience.com/>; were many of the DIPEX members are included as it is part of our MUSA European intention to get funding for this project. You are all invited to help construct the contents of this website with artistic transformations of your research, publications, as we have a section for our own projects and a section where we add interesting information on this topic of arts based knowledge transfer.

We are very proud to introduce you to Ana Pérez Ramos, who did her Bachelor Degree in Design with the project entitled: THE REFLECTION OF DESIGN IN TODAY'S SOCIETY. She constructed the identity of MUSA, the website and the preliminary design of a virtual space that could be used to create a virtual reality space to work in Intimate partner violence.



Erfaringene du har kan hjelpe oss

Marianne doing in-depth interviews with people living with mental illness themselves, or being affected and involved as a family member. Interviews are finalized and we are now in the process of analyzing them.

Spain

New projects

The module on ADHD has been launched and now it is completely available. It has been hard work with very limited resources. We have included on one hand the person's perspective and, on the other hand, the family's point of view: <https://www.dipex.es/nueva/tdah/>

We have plans to complete the pilot DIPEX Covid-19 project, as we have finally got funding from the Health Institute Carlos III (Spanish Ministry of Science) to do a full module with Covid-19 patients experiences, including long/persistent Covid-19, and carers of patients who were in ICU, or have lost a family member due to this disease.



Ana



MUSA seeks to enlighten the value of arts as vehicles to achieve an effective impact that provoke social changes and modify the perspective that society and individuals have been constructed in regards to suffering health problems. Arts contribute to construct human beings and have the power to change individuals and society.

MUSA aims to get a deep understanding of transformation methods and provide guidelines for future creations of artistic productions that aim to provoke societal changes. It has three main streams:

- | | | |
|--|---|--|
| <p>1. General perspective: identifying artistic productions that have generated new thinking, engagement and action in relation to health problems in order to contribute to their dissemination.</p> | <p>2. Methodological perspective: identifying and developing research that can contribute to the methodology, guidelines and spair criteria for how to transform scientific messages into artistic products that aims to provoke social changes.</p> | <p>3. Concrete perspective: producing and evaluating our own artistic creations that will be developed based on our research on different health topics that have a relevant impact on individuals and society.</p> |
|--|---|--|

We are simply a group of professionals in research areas with the purpose of expand our results and influence beyond the limits of scientific research in the real social world. Such a project requires a mix of healthcare professionals, social scientists, artists, and social influencers. We combine a deep methodological background with the capacity of innovation, social commitment and the ability to work as a team. Moreover, we share the idea of Eduardo Galeano.

"many little people, in little places, doing little things, can change the world."

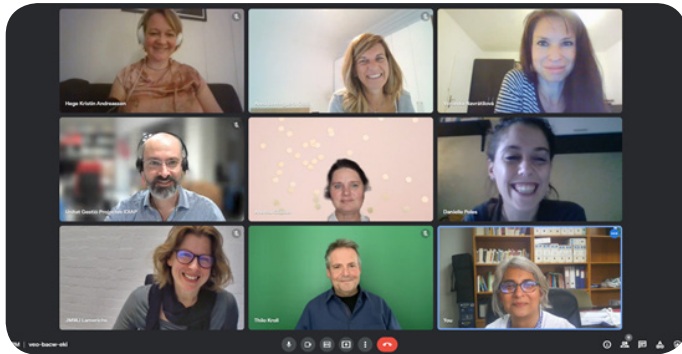
MUSA flyer

Other news

Finally, the collaboration between the groups from DIPEX Czech Republic, Ireland, Norway, The Netherlands, Switzerland and us, plus the three research groups from Barcelona and one from the Canary Islands, continue preparing for the MUSA project. We plan to send a new proposal to the Marie Curie Doctoral Networks (deadline 16th November 2021) touching the topic of Intimate Partner Violence.

In Spain, we continue trying for funding for the gender violence module, we tried in a National call that was denied, and now waiting for the decision from a local call. Keeping fingers crossed.

As we are a National association we include members who are from other cities of Spain. In this case we have the honour to have the support of Cristina Monforte, who is PhD in Health Sciences and teaches at the International University of Catalunya and Anna Berenguera who holds a Master degree in Public Health and works in the IDIAP Jordi Gol Primary Care Research Institute, both are based in Barcelona.



Online meeting 24th October of the MUSA team



Cristina



Anna

Recently we had to renew the DIPEX Spain Association executive members. Emilio continues to be the chair, and Vinita the secretary. We have a new vice-chair who is Mariola Marrero, a GP working on narrative medicine and has collaborated with DIPEX for a long time. We have three members who have been part of DIPEX Spain from the beginning: Pedro Rodríguez continues as the treasurer, he is a child psychiatrist; Carlos de las Cuevas, who is professor in Psychiatry at the University of La Laguna in Tenerife; and Miguel Angel Hernández, who is a GP working in the planning unit of the Canary Islands Health Care Services.

Switzerland

Living with a rare disease. Patients' and families' experiences



The term “rare diseases” (RD) covers a broad spectrum of illnesses that affect a large percentage of the total population in Europe. Estimated numbers range from 27 up to 36 million affected European citizens. A disease is labeled as rare when it affects at maximum 5 in 10.000 persons. Up to date between 7.000 and 8.000 rare diseases are recognized, most of them are of genetic origin. RD are often characterized by an early onset that leads to chronic conditions that impact not only quality of life but also lead to a significant decrease in life expectancy.

Coping with a RD presents many challenges to affected persons. Living with a RD can have an effect on individuals as well as their families and friends in multiple ways.



Mariola



Pedro



Carlos



Miguel Angel

There are many challenges that vary depending on the condition - from unexplainable symptoms despite many doctor visits, struggles with insurers to get access to expensive diagnostic tests, a lack not only of established treatment options but also social support more generally.

Given that patient experiences are still under-investigated and characterized by specific individual circumstances, our DIPEX module will help capture the complexity and breadth of the challenges RD patients and their relatives are confronted with while identifying sources of support and empowerment. In our project we listen closely to the stories of patients with three different sets of rare diseases – metabolic, neurological and connective tissues disorders. We ask them about their everyday lives, the care they receive and how they think it can be improved.

Our DIPEX module is incorporated in the University Priority Program of the University of Zurich ITINERARE: Innovative Therapies in Rare Diseases (<https://www.itinerare.uzh.ch>). This inter- and transdisciplinary research project fosters a close collaboration between medical sciences, natural sciences, and the humanities. Based on these collaborations we will deepen the insights of our interview study and contextualize our results in a broader research framework. Furthermore, we intend to work with patient organizations, patient representatives, and other clinicians to define key issues around diagnostic and treatment delays, lack of available interventions, access to health and social care services as well as perceived psychosocial and economic effects.

For further question or collaboration ideas contact Dr. Sebastian Wäscher



E-Mail contact: sebastian.waescher@ibme.uzh.ch

New module

Mental Health

In collaboration with the IBME and with the support of the Hans and Marianne Schwyn foundation, Anke Maatz (junior consultant, Psychiatric Hospital, University of Zurich), Yvonne Ilg (linguist, German Seminar, University of Zurich) and Henrike Wiemer (expert by experience, Psychiatric Hospital, University of Zurich) have started developing the module «Mental Health». The module embraces a transdiagnostic approach to mental health but focusses on experiences of psychosis and depression. We look forward to presenting details on the module in autumn 2022.



Anke Maatz, Yvonne Ilg, Henrike Wiemer

Publications

Jöbges S, Biller-Andorno N. (2021). Anwendung von Zwang in der Intensivmedizin [Use of coercive measures in the intensive care unit]. *Med Klin Intensivmed Notfmed*.116(3):205-209. German. doi: 10.1007/s00063-021-00800-9. Epub 2021 Mar 3. PMID: 33660019; PMCID: PMC8016755.

Jöbges S, Mouton-Dorey C, Ricou B, et al, (2021). Adult Patients' Experience of Coercion in Intensive Care: A Scoping Review, PREPRINT (Version 1) available at Research Square [<https://doi.org/10.21203/rs.3.rs-396302/v1>]

ChacónGómezYM, BruggerF, Biller-AndornoN. (2021). Parkinson's Disease and Deep Brain Stimulation Have an Impact on My Life: A Multimodal Study on the Experiences of Patients and Family Caregivers. *Int J Environ Res Public Health*.18(18):9516. doi: 10.3390/ijerph18189516. PMID: 34574440; PMCID: PMC8467519.

Chacón Gámez YM, Nikola Biller-Andorno N. (2021). Living With Parkinson's Disease and Connected to the Duodopa Pump: A Qualitative Study. *Qualitative Research in Medicine and Healthcare* 4 (3). <https://doi.org/10.4081/qrmh.2020.9427>.

Glässel A, Zumstein P, Scherer T, Feusi E, Biller-Andorno N. (2021). Case vignettes for simulated patients based on real patient experiences in the context of OSCE examinations: workshop experiences from interprofessional education. *GMS J Med Educ.* 38(5): Doc91. doi: 10.3205/zma001487. PMID: 34286071; PMCID: PMC8256122.

United Kingdom

Warm greetings to you all from the UK! While the pandemic has curtailed many of our in-person interviews, the UK team has (like the rest of you!) adapted to conducting online interviews over video and audio calls.

Amongst the current projects listed below, we'd like to draw your attention to the five doctoral research studies which will include Healthtalk outputs and the THIS Fellowship. We are really pleased that the approach continues to be interesting to doctoral students and their funders.

We have four current Covid-19 related studies with Healthtalk outputs: Covid-19 in diverse communities (led by Sue Ziebland, Oxford), Covid post-ICU (led by Lisa Hinton, Cambridge), Long Covid in Adults (led by Kate Hunt in Stirling, Scotland), and our most recently funded study, Long Covid in Families, led by Sue Ziebland. The findings from these four related studies will serve as both a source of information for people wanting to make sense of the ever-changing pandemic landscape and also help to inform ongoing care for those affected by COVID-19. We have been really pleased to welcome Cervantée Wild, a New Zealand postdoctoral researcher, who has recently joined the UK group for two years to work on the Long Covid in families study.

In September we were very fortunate to connect with our Slovak colleagues in Oxford for DIPEX accreditation training. This was the first in-person meeting with DI colleagues since Eynsham, Oxfordshire in November 2019. After the many diverted and cancelled plans over the past eighteen months, it was very exciting to meet as a group face to face to swap experiences, learn from each other, and share meals. Fingers crossed, we are looking forward to more in person meetings in the coming year!



DIPEX International accreditation training with the Slovakian team in Oxford, United Kingdom.

2020-21 in progress for Healthtalk & the new Social Care Talk platform

- HIV and breastfeeding (PI Tanvi Rai)
- Urogynaecological conditions (PI Abi McNiven)
- Gender identity (young people and parents) (PI Melissa Stepney)
- Vasculitis project link (Louise Locock)
- Knee replacements in the context of comorbidities MS&HERG lead (Abi McNiven)
- Fibromyalgia (Stefanie Doebel's doctoral research)
- Familial motor neurone disease (Jade Howard doctoral research)
- Painful periods (Sharon Dixon's doctoral research)
- Burns (Christia Huntington's doctoral research)
- Stillbirth (Danya Bakhbaki's doctoral research)
- Covid-19 ICU experiences (Annelieke Driessen's THIS Fellowship)
- Diverse experiences of Covid-19 (non-ICU) (PI Sue Ziebland)
- Long Covid in Adults (PI Kate Hunt, Stirling)
- Long Covid in young people and families (PI Sue Ziebland)

Social Care Talk studies

- Loneliness (with AEBCD in social care) (PI Sara Ryan, now Manchester Met University)
- Self-funders (PI Kate Baxter, York University)
- Formative Evaluation for SCT (PI Sue Ziebland)

Publications since 2020 report

We were pleased to be among several researchers (including our colleagues Rachel and Jane) asked to comment on ‘Collecting qualitative data during a pandemic’ by David Silverman

Adaptability and change: A rejoinder to ‘Collecting qualitative data during a pandemic’ by David Silverman – Sue Ziebland

From HT collections:

Talbot, A, Salinas, M, Albury, C, Ziebland, S. People with weight-related long-term conditions want support from GPs: A qualitative interview study. *Clin Obes.* 2021;e12471. <https://doi.org/10.1111/cob.12471>

Mikulak, M., Ryan, S., Ma, R., Martin, S., Stewart, J., Davidon, S., Stepney, M. Health professionals’ identified barriers to trans healthcare: a qualitative interview study. 2021. *British Journal of General Practice*, <https://doi.org/10.3399/BJGP.2021.0179>.

Ghio, D., Greenwell, K., Muller, I., Roberts, A., McNiven, A., and Santer, M. Psychosocial needs of adolescents and young adults with eczema: A secondary analysis of qualitative data to inform a behaviour change intervention. 2021, *Br J Health Psychol.*, 26: 214-231. <https://doi.org/10.1111/bjhp.12467>.

de Vere Hunt, I., McNiven, A., Roberts, A., et al. ‘Not just a piece of skin in front of you’—a qualitative exploration of the experiences of adolescents with eczema and psoriasis with healthcare professionals. *BMJ Open* 2021;11:e041108. doi: 10.1136/bmjopen-2020-041108.

Greenwell, K., Ghio, D., Muller, I., et al. Taking charge of eczema self-management: a qualitative interview study with young people with eczema. *BMJ Open* 2021;11:e044005. Doi: 10.1136/bmjopen-2020-044005.

de Vere Hunt I., McNiven A., McPherson T. A qualitative exploration of the experiences of adolescents with alopecia areata and their messages for healthcare professionals. *Br J Dermatol.* <https://doi.org/10.1111/bjd.19598>.

Ghio D., Muller I., Greenwell K., Roberts A., McNiven A., Langan SM., Santer M. ‘It’s like the bad guy in a movie who just doesn’t die’: a qualitative exploration of young people’s adaptation to eczema and implications for self-care. 2020. *Br J Dermatol.* 10.1111/bjd.18046.

Ip A., Muller I., Geraghty AWA., McNiven A., Little P., Santer M. Young people’s perceptions of acne and acne treatments: secondary analysis of qualitative interview data. *Br J Dermatol*, Vol 183h <http://doi.org/10.1111/bjd.18684>

de Vere Hunt, I., McNiven, A., and McPherson, T. ‘You’re harnessed into that rollercoaster no matter what’: a qualitative exploration of the psychological impact of alopecia areata in adolescence. 2020 *British Association of Dermatologists*. 183 (Suppl. 1), 88–93.

Mikulak, M. For whom is ignorance bliss? Ignorance, its functions and transformative potential in trans health. 2020, *Journal of Gender Studies*, DOI: 10.1080/09589236.2021.1880884.



DIPEX International training with the Slovakian team in Oxford, United Kingdom.

Methods etc:

Ziebland, S., Grob, R. and Schlesinger, M. Polyphonic perspectives on health and care: Reflections from two decades of the DIPEX project. 2020. *Journal of Health Services Research & Policy*, p.1355819620948909. <https://doi.org/10.1177/1355819620948909>

UK - DIPEX Charity

The Dipex Charity had our second ever runner take part in the London Marathon in October. Brendon Wittram raised more than £3,300 supported by tweets from our patrons veteran newsreader Jon Snow and actor Hugh Grant. Hugh promised to personally wash the hair of anyone who sponsored Brendon! It's not too late to add your sponsorship*. We're working on adding several new projects to healthtalk.org including Fibromyalgia and Vasculitis (with Aberdeen and Oxford) and Trans and gender diverse young people, and parents' experiences as well.

We worked with our HERN colleagues to launch the redesigned healthexperiencesUSA.org with new resources (including Breast cancer which launched recently). We also worked with our Dutch colleagues to relaunch Praten Over Gezonheid. Congratulations to all involved!

Author Sir Philip Pullman talked about the power of stories for this year's Ann McPherson Memorial lecture. Ann had many passions, and we always enjoy the opportunity to remember our late co-founder by hearing about one of them from an expert. If you missed it, you can watch a recording of the talk over on our blog.

We have also been working with a former healthtalk.org collaborator, Professor Lucy Smith at Leicester, to create an animated film for health professionals about signs of life in babies born at 20-24 weeks of pregnancy.

We plan to launch our upcoming sister site to healthtalk.org, socialcaretalk.org in early November with the first new module being on self-funders of social care. Another new section is well underway for the platform on Loneliness and is being developed by Sara Ryan and Melina Malli at Manchester Metropolitan University.

**The Dipex Charity cannot guarantee a personal hair wash from Hugh Grant should you sponsor Brendon.*

United States



Many of us have enjoyed seeing and connecting with many of you at virtual meetings over the past year. Here's hoping we can be in person again before long, but until then, we are grateful for how technology has helped the DI community to stay nourished throughout this difficult time.

Technology has similarly helped the Health Experiences Research Network (HERN) here in the USA remain connected and productive this year. Our Patient and Consumer Advisory Council has continued to meet, and to advise us on (among other things) language for our new website, and how to represent narratives about structural racism, other "isms," and resiliency. These conversations, and associated reading/study through our Learning Network, are ongoing in our community. Our new module on Breast Cancer has a topic summary on "Diversity, Fairness, and Taking Action." which reflects some of our work in this area. Be sure to follow along with HERN on Facebook (@HealthExperiencesUSA) and Instagram (@healthexusa).

We have been learning a lot from our pilot work on Experiences with Long COVID, and enjoying working with many of you on ideas for international analyses.

Processing gender diversity – parents’ experiences which will be launched next year along with the young people’s experiences.

As HERN looks to the future, building infrastructure here in the USA is a top priority. One strategy is training (led by our University of New Mexico node; see below for details). Another is through building a unified archive for the nearly 400 interviews (and growing!) we have now conducted (led by Oregon Health & Sciences University). We are also creating tools, such as Catalyst Films, for using our data to influence health and health outcomes directly (University of Wisconsin-Madison is leading this). Be on the lookout for new content on our site describing the national leadership roles staff across the country have taken on to launch HERN’s dissemination, capacity building and communication processes to the next level.

Modules

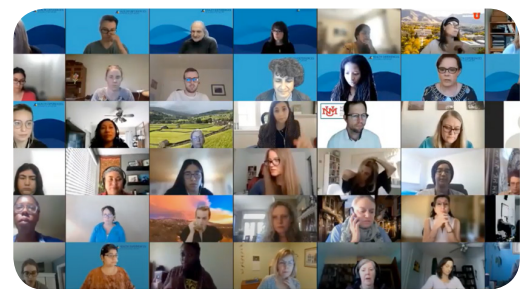
Here’s a snapshot of HERN’s projects, past, present and future. Each is being implemented by a multi-disciplinary team, and each team includes participants from at least 2 institutions within HERN. Our Clinical Trials module, which we anticipate going live in the first half of 2022, will be our first using data across multiple U.S. studies!

| <u>Completed Modules</u> | <u>Modules in Progress</u> | <u>Funded Modules</u> | <u>Planned but not yet Funded</u> |
|---|---------------------------------------|---------------------------------------|--|
| Young Adults’ Experiences with Depression | Gulf War Illness | Gulf War Veterans’ Health Experiences | Gender Affirmative Surgery for Transgender and Non Binary People |
| Traumatic Brain Injury in Veterans | Young Adults’ Experiences with Cancer | | Full module on Long COVID |
| Cancer Risk that Runs in Families | Multiple Sclerosis | | Cystic Fibrosis |
| Experiences with Breast Cancer | Clinical Trials | | Autosomal Recessive Polycystic Kidney Disease |
| Childhood Cancer* | Firearm Injuries | | Colorectal Cancer |

Our network also has a number of pilot projects in the field (experiences with psychosis; Long COVID; adolescent experiences of reproductive health; end stage renal disease; autosomal recessive polycystic kidney disease; experiences with kidney donation) and others on the horizon or under grant review.

Learning and Training

HERN held its first virtual training in May of this year (photos below) . We were joined by 52 new researchers and team members from around the country, including a number of people focused on health equity.



Our Learning Network, which is open to anyone in the U.S. who has been trained by either HERG or HERN, continues to meet bi-monthly and to thrive. Topics we examined together this year included:

- Young Adults Experiences with Depression Catalyst Film – Review and Implementation
- Experiences with Institutional Review Board (IRB) – Challenges and Strategies
- Interviewing during the Pandemic
 - o Integrating COVID-19 Questions
 - o Shifting to Virtual Interviews
 - o Rapport Building Strategies
- Formalizing Interview Questions around Race and Identity
- Participant Material Review – Timeline and Ethics

HERN’s post-docs, doctoral students, and master’s students, continue to work on projects critical to the Network’s mission. One student received Federal funding to develop a catalyst film based on pilot HERN work and to conduct a workshop with healthcare workers. Another was funded to do the same with medical students. Others are using HERN data to look at inequities in hospital care for children; to scope out new modules; to develop a research agenda around young adults’ experiences with cancer; and to explore “zones of conflict” between clinical recommendations and insurance coverage related to hereditary cancer risk.

Interventions and Evaluation

Our first “catalyst film” (rather than “trigger film”) from the depression module is live on our website. Materials from our new “Cancer Risk that Runs in Families” module are being used to create a grant-funded intervention designed to address disparities in the uptake of genetic testing. We have additional grants under review which would create and evaluate interventions designed to improve equity of genetic/genomic testing. We also received funding from the National Cancer Institute to use DIPEX methods to understand experiences with smoking and smoking cessation, and create a catalyst film for use improving health outcomes.

Publications and Presentations

Publications

1. Christensen V, Parker K, Cottrell E. Leveraging a qualitative data repository to integrate patient and caregiver perspectives into clinical research. *J Clin Transl Sci.* 2021;5(1):e155. Published 2021 Jul 21. doi:10.1017/cts.2021.822
2. Grob, R., Evered, J. “What is emerging for qualitative research in the COVID-19 emergency? A rejoinder to ‘Collecting qualitative data during a pandemic’ by David Silverman.” *Commun Med.* June 2021;17(1):85-87. DOI: <https://doi.org/10.1558/cam.19752>

Many additional manuscripts from the US team are under review, or in process.

Presentations

Grob, R. “Research + Impact: Diverse Experiences with Breast Cancer.” *Breast Friends Cancer Support Network.* 2021. Available at: <https://www.voiceamerica.com/episode/133812/research-impact-diverse-experiences-with-breast-cancer>

“Remote Trial Management.” M. Krancari, co-presenter at *2021 Northwest Clinical Research Conference*; October 2021

“Elevating patient voices: An innovative approach to understanding and disseminating patient health experiences.” E. Cottrell and M. Helfand, co-presenters at *2021 OHSU Department of Medicine, Grand Rounds Portland, OR*; October 12, 2021

“The Power of Patient Stories.” R. Grob, invited plenary presenter at *2021 AHRQ CAHPS Research Meeting: Advancing the Science and Implementation of Patient Narratives*; Virtual, October 7, 2021

“Bringing patients’ voices to American healthcare: An innovative approach to understanding and disseminating health experiences.” E. Cottrell and T. Prescott, co-presenters at *2021 OCHIN Grand Rounds*; February 2021

“Remote Trial Management.” M. Krancari, presenter at *2020 OHSU Internal RA Meeting*; 2020

See you soon!

A number of us will be at the virtual DI meeting later this fall; we look forward to connecting with many of you there.