



**DIPEx International**

# Newsletter 2023



## Introduction from the chair

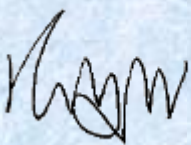
*Dear colleagues,*

*What an outstanding group of people you are. On these pages -- and there are many, because you have been doing so much! -- you will read about new modules, new methodological innovations, new researchers and graduate students, new initiatives, new trainings, new publications. In line with our collective commitment to visual methods, you will also see many photographs that put faces to names and help us get a flavor for one another's workplaces, endeavors, and teams.*

*A special treat in this issue of our newsletter is an update on the now-complete special issue of *Social Science and Medicine: Qualitative Research in Health* focused on the work people in eight of our member countries did collectively around COVID-19. This is a stellar example of the kind of contributions we can make as an international qualitative research community: I encourage those of you who have not yet perused the issue to take a look. Please also give thought to what kinds of shared endeavors we should take on next. A special issue on the marriage of art and science in our work? One on equity issues raised within our studies and by our methodology? What are your ideas?*

*It was a memorable joy to see so many of you in the Czech Republic last fall. Please mark your calendars to be together again for our on-line mini-meeting in 2024 (**Wednesday 20<sup>th</sup> Nov, Tuesday 26<sup>th</sup> Nov, Thursday 5<sup>th</sup> Dec.**), and in person in Norway (!!!) **2-6 June, 2025.***

*Very warmest wishes from me to each and all of you,*



*Rachel*

## DI meeting 2024 – On-line

**Bringing the whole community together online, overcoming time zone challenges.**

**Save the dates:**

- **Wednesday 20th Nov,**
- **Tuesday 26th Nov,**
- **Thursday 5th Dec.**

Specific times for each zone coming soon.

**Light Touch Approach:** Organizing 3 sessions of 1.5-2 hours each, reflecting feedback and the unique nature of this interim year event.

**Content Areas:** Methodological issues, new global projects, 'dangerous ideas' and innovations, networking.

**Organizing Committee:** Volunteers stepping up to work on content and format.  
Huge thanks to those who volunteer!

## DI BOD & AGM meeting 2024 – on-line

Dear Directors,

You are invited to the DI Board of Directors and Annual General Meeting 2024.

Date: November 12, 2024

Time: 13:00 CET

Format: Online

We look forward to your participation.

<https://cesnet.zoom.us/j/93454431886?pwd=00PyxYk4Ph84cNmDVvn53m7bcf5htJ.1>

Meeting ID: 934 5443 1886

Passcode: 427443

## Save the date DI meeting 2025!

**WELCOME TO DIPEX NORWAY!**

**June 2 – 6 2025, DIPEX 2025 meeting will take place in Tromsø, Norway.**

**Venue** - Conference hotel is approximately 45 minutes' drive from the airport, follow this link if you want to read more about the venue: <https://sommaroy.no/>

**Special Issue of Social Science and Medicine  
QRH**

Members of the DIPEX international community have collaborated over the past two years to produce cross-country comparisons of Covid-19 patient experiences for a special issue of the journal *Social Science and Medicine: Qualitative Research in Health*. Co-editors Rika, Alicia, Rachel, Mark, Anna (Dowrick), and Sue have been immensely impressed by the dedication to engaging with these comparative studies for the special issue.

Dowrick, A., Evered, J.A., Navarro Dias de Souza, A., Thier, A., Inês Gandolfo Conceição, M., Holmberg, C. & Mahtani-Chugani, V. 2023, "Sharing uncertainty: Comparing patient narratives of help-seeking in the first year of the Covid-19 pandemic across the UK, USA, Brazil, Germany and Spain", *SSM - Qualitative Research in Health*, pp. 100306.

Dowrick, A., Grob, R., Sawada, A., Thier, A., Holmberg, C. & Sato, R.S. 2023, "Navigating responsible bio-political citizenship: Cross-country comparison of stigma in Covid-19 illness narratives in Germany, Japan, the UK and the USA", *SSM. Qualitative research in health*, , pp. 100291.

Driessen, A., Navarro de Souza, A., Castellanos, M. E. P., Tuma de Oliveira, M. V., Carvalho, E. L., & Hinton, L. (In Press). Navigating uncertainties in critical care with Covid-19: A cross-country analysis of patient narratives from Brazil and the United Kingdom. *SSM – Qualitative Research in Health*, No Volume/Issue. <https://doi.org/10.1016/j.ssmqr.2023.100363>

Evered, J.A., Castellanos, M.E.P., Dowrick, A., Camargo Goncalves Germani, A.C., Rai, T., Navarro de Souza, A., Qureshi, K., Gandolfo Conceição, M.I., Cabral, I. & Grob, R. 2023, "Talking about inequities: A comparative analysis of COVID-19 narratives in the UK, US, and Brazil", *SSM - Qualitative Research in Health*, vol. 3, pp. 100277.

Heath, J., Moran, M., & Dowrick, A. (2024). Examining qualitative cross-country comparative analysis in health: Reflective insights and methodological considerations. *SSM – Qualitative Research in Health* (in press).

Holmberg, C., Nettleton, S., Sato, R. S., Mahtani-Chugani, V., Driessen, A., Ormel, I., Wynn, M., Verheij, N., Alma, M., & Their, A. (2023). Doing isolation – caring Citizens. A cross-country comparative analysis of patient experiences with isolation practices during the early phase of the Covid-19 pandemic. *SSM – Qualitative Research in Health*, 4(100364), 1–10. <https://doi.org/10.1016/j.ssmqr.2023.100364>

Maclean, A., Hunt, K., Brown, A., Evered, J.A., Dowrick, A., Fokkens, A., Grob, R., Law, S., Locock, L., Marcinow, M., Smith, L., Urbanowicz, A., Verheij, N. & Wild, C. 2023, "Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy", *SSM. Qualitative research in health*, vol. 3, pp. 100207.

Qureshi, K., Evered, J.A., Toyomoto, R., Urbanowicz, A., Sawada, A., Smith, L., Sato, R.S. & Rai, T. 2023, "Covid-19 trouble at work: A comparative qualitative analysis of disclosure, sickness absence and return-to-work in the UK, the USA, Australia and Japan", *SSM - Qualitative Research in Health*, vol. 4, pp. 100307.

Wild, C.E.K., Conceição, M.I.G., Iwakuma, M., Lewis-Jackson, S., Toyomoto, R., de Souza, A.R.N.D., Mahtani-Chugani, V., Sato, R.S. & Rai, T. 2023, "Perceptions of government guidance and citizen responses during the COVID-19 pandemic: A cross-country analysis", *SSM - Qualitative Research in Health*, vol. 4, pp. 100308.

Ziebland, Sue; Sakuma Sato, Rika; Grob, Rachel; Dowrick, Anna; Navarro Dias de Souza, Alicia Regina; Spitale, Giovanni; Schlesinger, Mark (2024). Cross country analysis of qualitative interviews: Developing a method, a community

and an understanding of how Covid has been experienced around the globe. *SSM - Qualitative Research in Health*:Epub ahead of print. DOI: <https://doi.org/10.1016/j.ssmqr.2024.100396>

And the amazing appendix pulled together by Rika Sakuma Sato with a helping hand from Anna Dowrick.

New publications since last newsletter:

Kasadha, B., Tariq, S., Freeman-Romilly, N. et al. "We decided together": a qualitative study about women with HIV navigating infant-feeding decisions with the father of their children. *BMC Pregnancy Childbirth* 24, 41 (2024). <https://doi.org/10.1186/s12884-023-06198-w>

Rai, T., Kasadha, B., Tariq, S., Keating, S., Hinton, L., Namiba, A., Pope, C. Infant feeding as a transgressive practice in the context of HIV in the UK: A qualitative interview study, *Women's Studies International Forum* 101, 2023, 102834, <https://doi.org/10.1016/j.wsif.2023.102834>.

Kasadha B, Tariq S, Nyatsanza F, Freeman-Romilly N, Namiba A, Rai T. Stakeholder engagement is essential to maximise the impact of research on infant feeding in the context of HIV. *Therapeutic Advances in Infectious Disease*. 2021;8.

<https://journals.sagepub.com/doi/10.1177/20499361211057970>

Dowrick, A., Qureshi, K., & Rai, T. (2024) Negotiating un/sanitary citizenship: the reception of UK government COVID-19 public health messaging by racialised people highly exposed to infection, *Anthropology & Medicine*, DOI: 10.1080/13648470.2023.2274710

Qureshi, K., Dowrick, A. & Rai, T. (2023). Immunisations and imagining imperilled fertility: Women's trials of COVID-19 vaccines and reproductive/citizenship transgressions in pandemic times. *Women's Studies International Forum* 100, 2023, 102739, <https://doi.org/10.1016/j.wsif.2023.102739>.

MacLean A, Wild C, Hunt K, et al. (2023). Impact of Long Covid on the school experiences of children and young people: a qualitative study. *BMJ Open* 13:e075756. doi: 10.1136/bmjopen-2023-075756

Maclean, A., Hunt, K., Brown, A., et al. (2022). Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy. *SSM - Qualitative Research in Health* 100207. <https://doi.org/https://doi.org/10.1016/j.ssmqr.2022.10020>

## Australia

### Projects

Borderline Personality (BPD) as Social Phenomena

The latest Healthtalk Australia online resource, Borderline Personality as Social Phenomena, was launched in November 2023 by Mary O'Hagan, Director of Lived Experience at the Victorian State Government Department for Health at an event hosted by RMIT University. The resource is a dynamic platform that illustrates people's life experiences in a multi-faceted way using audio clips, written statements, and bespoke video material and soundscapes. It has been organised into five main sections that reflect the most significant aspects of people's experiences including receiving and living with a diagnosis of BPD among other diagnoses, traumatic histories connected with mental distress, experiences of seeking care within health and social care systems, and the social supports and practices people found beneficial outside of the healthcare system.

Another output from the project was a verbatim play titled "Borderline". The theatre play was based on the project's lived experience interviews. The play was performed across three nights at RMIT University's Kaleidoscope theatre in October 2023, during BPD Awareness Week. The play was an opportunity to challenge the stigma associated with mental distress and a creative way to present key findings from the narrative interviews.

Other outputs include a number of journal article publications co-written by the research team, which are currently under review in key social sciences journals.

The project is funded by the Australian Research Council Linkage Project scheme and guided by a Lived Experience Advisory Group and an Advisory Group including

researchers, health practitioners and policy makers. Partner organisations on the research include the Victorian Department of Health, Spectrum, Orygen, National Mental Health Commission, Mental Health Victoria, Lived Experience Australia, Mind Australia, and Neami National. Professor Renata Kokanović, Director of HTA, led the project in collaboration with an interdisciplinary group of co-investigators, including project researchers Dr Emma-Louise Seal and Dr Tamara Borovica.

A link to the resource is provided here: <https://www.healthtalkaustralia.org/bpd/#>  
Welcome

### Covid-19

2023 saw two publications emanating from the international comparison studies conducted into people's experiences of Covid-19. On the home front, we are putting the finishing touches to a short film of the pilot study we conducted exploring Australian's experiences of the pandemic.

### Publications

Flore, J., Kokanović, R., Johnston-Ataata, K., Hickey, M., Teede, H., Vincent, A., & Boyle, J. A. (2023). Care, choice, complexities: The circulations of hormone therapy in early menopause. *The Sociological Review*.  
<https://doi.org/10.1177/00380261231179307>

Vincent, A., Johnston-Ataata, K., Flore, J., Kokanović, R., Hickey, M., Boyle, J. A & Teede, H. (2024). A qualitative study of work and early menopause: 'On-the job' experiences and career trajectories. *Maturitas*.  
<https://doi.org/10.1016/j.maturitas.2024.101079>

## Brazil

### Website

We have launched a new online resource that is called catalyst films to disseminate knowledge especially to patients and health professionals from Brazilian unified public health system (SUS). The first short film is based on emotional suffering narratives of participants treated in therapeutic groups in primary care. The second film is about the narrative of women victims of intimate partner violence and the care provided by the primary health care in the city of Rio de Janeiro. Active patient participation and engagement are what makes catalyst films such a useful and unique resource for health service groups.

<http://www.narrativasesaude.ccs.ufrj.br/publicacoes-apresentacoes-e-midia-copy/>

### Covid Modules

Brazilian members of DIPEX team have developed different research projects related to COVID. 54 persons who were hospitalized with COVID, most of all in ICU wards gave rise to the SEVERE COVID-19 MODULE.

<http://www.narrativasesaude.ccs.ufrj.br/covid-19-grave-introducao/>.

Forty health care professionals who work in public primary care were interviewed and a module is being built on their experience working on the frontline during the pandemic.

<http://www.narrativasesaude.ccs.ufrj.br/covid-19-aps-introducao/>

At all we did 142 interviews related to COVID although we did not get funding. Our students and the DIPEX international meetings on COVID encouraged our research work.

### Papers published ON COVID

We are happy to announce the papers that Brazilian DIPEX members participated on cross-country comparative analysis of patient experiences during the Covid-19 pandemic.



Two members of DIPEX Brazil, Ines Gandolfo and Alicia Navarro de Souza, also authored a chapter titled “Survivors’ Narratives of Severe COVID-19: What Can We Learn from Them?” that was published in Portuguese in a freely accessible e-book. The e-book compiles a collection of texts under the title “Pandemic and Mental Health: Clinical, Educational, and Institutional Challenges.” The chapter was co-written with two university students (Maria Vitória Oliveira and Ranieli Sousa) associated with the respective members. The students actively participated in building the severe COVID-19 module and writing the chapter. In this text, we briefly present and describe the pioneering and innovative experience of the DIPEX, focusing on the module dedicated to narratives in severe COVID-19.

Conceição, Maria Ines G.; Oliveira, Maria Vitoria T.; Sousa, Ranieli C. Gomes De; Navarro De Souza, Alicia. Narrativas de sobreviventes de covid-19 grave: o que podemos aprender com eles? In: Katia Cristina T R Brasil; Cristineide Leandro-França; Regina Lucia S Pedroza e Silvia Renata Lordello. (Org.). Pandemia e Saude Mental: desafios clínicos, educacionais e institucionais. 01 ed. Brasilia: TechnoPolitik, 2023, pp. 199-213. Retrieved from <http://www.technopolitik.com.br>

Some of our undergraduate students went to the annual Brazilian Congress of Medical Education (COBEM) in Foz do Iguaçu and They Presented: The Virtual Sharing Of Narratives And The Training Of Health Professionals: Leprosy Module.

#### **DIPEX International Annual Meeting in the Czech Republic – Hluboka nad Vlavou, September 2023**

It was a pleasure to be part of this event which brought together twelve countries and Brazil was there with their Dipex members Marcelo Castellanos and Alicia Navarro de Souza. During the meeting, in addition to sharing the activities of the Brazilian DIPEX group, we addressed research questions that are being discussed at DI, such as the importance of thinking about how positionalities and voices are present in DIPEX research and modules. Furthermore, the DEI group once again opened a space to engage DIPEX members in a moment of self-reflection about their experiences



#### **Research Project**

During 2023 our team also developed a research protocol called “The experience of black people in training at public universities in the area of health in Brazil: dialogues for belongingness and care”. The objective of the study is to understand the experience of black people undergoing



university training in the health sector in Brazil, with and from them. We will seek to identify racist and anti-racist practices in the experiences of these black students and understand the difficulties faced and strategies found to overcome them and build belonging. The proposal presented has high potential to contribute to the evaluation and guidance of affirmative policies underway in Brazil, aiming to increase their impact on the inclusion and qualified retention of black people in the health sector, with positive repercussions for the SUS. Being an inter-institutional project, with inter-regional reach, with a multi-professional and diverse team in professional and ethnic-racial terms increases its power and reach. The project ultimately aligns with Sustainable Development Goals 10 - reducing inequalities and 3 - good health and well-being of the 2030 Agenda. Seven Universities are to be involved within the project, five of them partners in DIPEX-Brazil: Universidade de São Paulo, Universidade Federal do Recôncavo da Bahia - UFRB, Universidade Federal de



Santa Catarina - UFSC, Universidade Federal do Rio de Janeiro - UFRJ, Universidade de Brasília - UnB, Universidade Estadual Paulista Júlio de Mesquita Filho – UNESP and Universidade Federal da Bahia – UFBA. Unfortunately, we haven't succeeded in getting funds for the development of the research. However, we follow looking for funding.

Finally, DIPEx Brazil has a new member Andreza Pereira Rodrigues who did the HERN training in February 2024. Andreza has been teaching at the Department of Public Health Nursing, Anna Nery School of Nursing of Federal University of Rio de Janeiro since 2018. She has been doing research on Reproductive Health and reproductive life events among women since 2008. <https://orcid.org/0000-0002-1873-5828>.

## Canada

**Hello everyone – greetings and news from Canada!**

**CURRENT MODULES:** We have three modules near completion – to be posted online this Summer/Fall:

**Experiences of Long COVID.** Our module on experiences of long COVID, funded by the Canadian Institutes of Health Research, will be launched this summer (**Linda Rozmovits and Michelle Marcinow**), based on 42 interviews with adults across 8 provinces and territories. We received a secondary grant from another CIHR-funded project to conduct interviews with decision makers responsible for leading service changes for long COVID in provinces and territories across Canada.

**'From the heart': women's experiences of heart failure.** This module is also in the final preparatory stages to launch this summer (**Heather Lannon, Jane Sandercock, Jason Nie and Michelle**

**Marcinow**), based on 30 interviews with women across 7 provinces.

**Mental health and pregnancy.** We have now completed 32 interviews across 4 provinces about experiences of mental health problems during and after pregnancy (**Ilja Ormel and Ana Keller**). Analysis will be completed in the coming months and we will secure additional funding to prepare and launch a module.

## OTHER PROJECTS INVOLVING PERSONAL EXPERIENCES

**Medical cannabis and chronic pain.** Our team has been involved in a few medical cannabis-related initiatives. The narrative synthesis on patient experience of medical cannabis has now been resubmitted – with huge thanks to **Martina Breuning** (Germany) for taking the lead on this one, and to **Jason Nie** for stellar support! Lorraine Smith (AU) and Susan received two University of Sydney – University of Toronto collaboration awards to conduct focus groups, interviews and symposia with stakeholders in each of our countries. We note that (perhaps coincidentally) the recent report of the federal expert review of the Canadian *Cannabis Act* seems VERY well aligned with the recommendations of our Fall 2023 roundtable. We have been inspired to resubmit our proposal for a module on patient experience of using medical cannabis for chronic pain – likely Fall 2024.

**Transitions and health during war: experiences of Ukrainian refugees.** Our team helped to organize (with **Lorraine Smith** and **Joel Montanez**) a training initiative to support qualitative researchers interviewing people from Ukraine displaced due to war (planning a follow-up perhaps Fall 2024). With special thanks to our Ukrainian partner organizations and **Alona Lypovsky** (student with lived experience who provided essential contextual and cultural background for this

session. We received a small grant to conduct five interviews for the pilot study of Ukrainian refugees, data collection is complete and analysis in process.

**Pregnancy and birth during COVID.**

Susan supported a small hospital-based project on patient experience of birth during COVID, led by first-time nursing researchers. Paper has been accepted for publication.

**Experience-based co-design in paediatric intensive care.**

Susan is a co-investigator on an experience-based co-design project and is transitioning to PI. A challenging but insightful project!

**Experiences of rehab personnel caring for patients in a COVID-19 hot zone.**

(Susan, Dahlia Kairy, Joel). Data analysis underway by 2 graduate students (Rosemarie Boudreau and Rebecca Benyk).

**Sharing the lessons of a lifetime with an orphan disease during the process of assisted dying.**

Joel, Nicolas Gulino. Recruiting.

**Sharing family experiences during the process of assisted dying.**

(Rosemarie, Joel). Project accepted as part of Rosemarie's Individualized Master's Program.

## **UNSUCCESSFUL PROPOSALS**

As always, we are learning from our unsuccessful attempts to obtain funds for health experiences initiatives. In 2023/24, we wrote grants which ranked well but not high enough to receive funding from granting agencies on women's experiences of gynaecologic cancers, using arts-based approaches for conversations on dying and death with young adults, and experiences of Ukraine refugees of transition and health. Try, try again!

## **IN THE WORKS**

We are developing a proposal for a module on women veterans' experiences of chronic pain to submit June 2024 (led by **Émilie Dionne**). We are planning to develop a proposal to obtain network/infrastructure funding for Health Experiences Research Canada, and to resubmit a medical cannabis and chronic pain proposal. Together with DI colleagues from eligible countries – Germany (**Christine Holmberg** and **Luisa Wagenschwanz**), UK (**Sue Ziebland**, **Lisa Hinton** and **Anna Dowrick**), Japan (**Rika Sato**, **Rie Toyomoto**, **Ryoko Hatanaka**, **Setsuko Sugano**, and **Takuya Matsushige**), and our Canadian team (**Susan Law**, **Ilja Ormel**, **Matthew Hunt**, and **Kenneth Southall**), an application was submitted to the ORA8 opportunity to explore how social scientists can better collaborate across countries in times of public health crises. Funding decisions in September 2024. Fingers crossed!

## **WEB AND SOCIAL MEDIA UPDATES**

Since 2018, over 125,000 people have accessed our web site, with about 6,400 users in 2024 so far. The majority of people visiting [healthexperiences.ca](https://healthexperiences.ca) appear to be based in France (interestingly!), with significant numbers from Canada and the United States. Since January 2024, our website has accrued over 15,000 page views and has been accessed from 121 countries around the world. Our social media presence, particularly on Instagram, has seen remarkable growth and engagement over the past year. We have experienced an 835% increase in impressions (views) and a massive surge in the number of accounts reached (+4,533%). Engagement has also soared, with a 200% increase from non-followers and a 120% increase from followers. Our Instagram followers are predominantly female (80%), aged 35-44, with a strong presence across Canada, and from the US, Brazil, the UK, and France. Currently, we have 266 followers on Instagram and counting! On

LinkedIn, a singular repost by a team member sharing content from the Health Experiences page garnered 1,674 impressions, showcasing the potential of cross-platform promotion - an initiative we will explore further as we refine our social media strategy. We have also been resharing our work through the DiPEX LinkedIn page, which has helped increase impressions for our LinkedIn content. Instagram remains our primary platform, and we also maintain an active presence on Facebook, Twitter, and LinkedIn. Introducing Reels and short-form video content has significantly boosted our reach on Instagram. Additionally, we have started posting content in both English and French on Instagram and Twitter to broaden our reach and inclusivity. We encourage any/all to follow us on Instagram, Facebook, Twitter, and LinkedIn to stay updated with our work! With thanks to **Ryan Caulfeild**, **Yousra Lakhani**, and **Graham Gould** for their stellar support on these activities.

### **DIPEX INTERNATIONAL COLLABORATORS MEETING, Czechia**

Heather Lannon and Susan Law attended the 2023 DI meeting in beautiful Czechia. Susan presented with Lorraine Smith on the development of the training session for the Ukrainian refugee project, Susan presented on the session organized with Canadian journalists on lessons for qualitative researchers and, Heather presented on our progress with the heart failure project.

### **HERC TEAM UPDATES**

Welcome to **Jane Sandercock**, Research Associate, who has joined us to support the analysis and publication of our heart failure module, as well as to **Kenny Southall**, Research Associate, working to support our work with Ukrainian refugees. Most recently, **Fredrick Vokey**, Research Professional at Université Laval joins us as part of Emilie's team (see below).

**Michelle Marinow** has been on maternity leave – congrats on the arrival of her baby boy Max! In the Fall of 2023, our team welcomed three undergraduate students for their practicum in their final year of health studies at the University of Western Ontario – **Graham Gould**, **Kayla Krolkowski**, and **Daniela Senese**. They have been helping with our social media, literature reviews for various projects, the medical cannabis project, and a review of patient engagement training initiatives in Ontario. A very special welcome to **Émilie Dionne** who has been a member of various project teams and has officially joined Susan as Co-Director of Health Experiences Research Canada. Emilie is a sociopolitical scientist, feminist thinker, and qualitative health researcher at the VITAM Research Centre in Sustainable Health (Centre de recherche en santé durable) in Quebec City, and adjunct professor in the Department of Sociology at Université Laval. Her research interests include person-centred care, ethics of vulnerability, critical qualitative methodology, feminist bioethics, participatory action research. Wonderful to welcome Emilie to the leadership for HERC – we have many plans in the making for the future of our team and work, so stay tuned. 😊

### **SELECTED CONFERENCE PRESENTATIONS –2023/24**

Nie JX, Smith L, Clark H, Kalocsai C, Schwartz R, Smith N, Gould G, Law S. *Access to medical cannabis in Canada: exploring policy, clinical and patient advocacy perspectives*. Poster presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.

Law S, Lypovsky A, Montanez J, Ormel I, Smith L. *Interviewing people with traumatic experience: an approach to preparing qualitative researchers for an international Ukrainian refugee project*. Oral presentation at the 2024 Annual

CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.

Sandercock J, Lannon H, Nie JX, Marcinow M, Montague J, Ratz, J, Law S. *From the heart: Canadian women's lived experiences of heart failure*. Oral presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.

Law S, Rozmovits L, Christopoulos T, Weeks L, Cheung A, Gibbens M, Décary S. *Improving health system design for people with long COVID or Post-COVID Condition: perspectives and experiences of change leaders in Canada*. Oral presentation at the 2024 Annual CAHSPR Conference. Ottawa, Ontario, Canada. May 14-16, 2024.

Ganty P, Ware M, Busse J, Law S. *The role of cannabinoids in current pain practice and future implications*. Panel presentation at the 2024 Canadian Pain Society Annual Symposium. Ottawa, Ontario, Canada. May 27-30, 2024.

DIPEX International Collaborators Meeting 2023. *From the heart: Canadian women's lived experiences of heart failure*. Lannon H, Law S. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.

DIPEX International Collaborators Meeting 2023. *Interviewing people with traumatic experience - Refugee project: Experiences of Ukraine displaced persons due to war*. Law S, Smith L. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.

DIPEX International Collaborators Meeting 2023. *Are there lessons for qualitative researchers from journalists?* Law S. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.

DIPEX International Collaborators Meeting 2023. *The persistence of stigma in the lived experiences of people using medical cannabis: a scoping narrative review of the qualitative literature*. Breuning M, Nie J, Schlesinger M, Smith L, Lavie-Ajayi M, Babinski S, Law S. September 18-21, 2023. Hluboká nad Vltavou, Czechia. Oral presentation.

Public Health Palliative Care International Conference 2024. *Using narrative data to engage young adults in conversations about dying and death*. Smith, K., Law., S., Blanchard, P., Widger, K., & Stajduhar, K. October 2024, Switzerland. *Accepted*.

International Conference on Clinical Ethics and Consultation & Canadian Bioethics Society 2024. *Using narrative data to engage young adults in conversations about dying and death*. Smith, K., Law., S., Blanchard, P., Widger, K., & Stajduhar, K. Montreal, Quebec, Canada. *Submitted*.

University of British Columbia Women's+ Health Trainee Research Conference. *From the heart: Canadian women's experiences of heart failure*. Lannon H, Marcinow M, Nie J, Wright D, Law S. Virtual conference, June 14, 2023. Poster presentation.

Canadian Association of Perinatal and Women's Health Nurses (CAPWHN) National Conference. *A qualitative study of the lived experiences of pregnant persons during the early phases of the COVID-19 pandemic*. Hoosein S, Winchester P, Smith N, Law S. Winnipeg, Manitoba, April 27-28, 2023. Poster presentation.

#### **PUBLICATIONS – since previous newsletter** (students underlined)

Breuning M, Nie J, Schlesinger M, Smith L, Lavie-Ajayi M, Babinski S, Law S. *The persistence of stigma and other challenges in the lived experiences of people using medical cannabis: a thematic synthesis of*

*the qualitative literature. Submitted to Journal of Psychoactive Drugs May 23, 2024. ☺*

Gilbert M, Pytka-Jones R, Galino N, Ormel I, Dahlia K, Law S, Montanez J. I would not want my leg back”: Living experiences of adult amputees. *Submitted to Rehabilitation Psychology, March 17, 2024. Revisions requested May 2024.*

Hoosein S, Winchester P, Babinski S, Smith N, Bahvsar P, Law S. An exploratory qualitative study of perinatal experiences in an acute setting during early phases of the COVID-19 pandemic. *Submitted to the Journal of Patient Experience October 20, 2023. Accepted for publication with minor revisions May 14, 2024.*

Marcinow M, Sandercock J, Cadel L, Singh H, Guilcher S, Dowedoff P, Maybee A, Law S, Fancott C, Kuluski K. A qualitative study exploring how patient engagement activities were sustained or adapted in Canadian healthcare organizations during the COVID-19 pandemic. *PLOS ONE* 2023, 18(3): e0282890. <https://doi.org/10.1371/journal.pone.0282890>

Macarthur C, Van Hoorn R, Lavis J, Straus S, Jones N, Bayliss L, Terry AL, Law S, Victor C, Prud’homme D, Riley J, Stewart M. Training and capacity development in patient-oriented research: Ontario SPOR SUPPORT Unit (OSSU) initiatives. *Res Involv & Engagem* (2023) 9:5. <https://doi.org/10.1186/s40900-023-00415-8>

Rozmovits L, Marcinow M, Ormel I, Tang T, Mansfield E, Kuluski K, Marwaha S, Law S. Living with long-COVID in the community during the first wave of the pandemic: Lessons for healthcare providers and policy makers. *Patient Experience Journal* 2023; 10(1): 115-123. <https://doi.org/10.35680/2372-0247.1714>.

Charlebois K, Law S. Optimizing the discharge process from internal medicine: understanding the challenges faced by clinicians and staff. *Health and Social Care in the Community*, 2022; 00, 1-10. <https://doi.org/10.1111/hsc.14023>

Rennick J, Buchanan F, Cohen E, Carnevale F, Dryden-Palmer K, Fontela P, Patel H, Razack S, St-Saveur I, Law S. Towards enhancing Pediatric Intensive Care for Children with Medical Complexity (ToPIC CMC): A mixed methods study protocol using Experience-Based Co-Design. *BMJ Open*, 2022; 12:e066459. <http://dx.doi.org/10.1136/bmjopen-2022-066459>

## **WITH THANKS TO OUR FUNDERS & SPONSORS**

Trillium Health Partners

St. Mary’s Hospital Foundation

Ontario SPOR SUPPORT Unit

Canadian Institutes of Health Research

University of Toronto

## **Czech Republic**

The Czech team is continuing to finalize the DIPEX modules, with several of them ready for completion and awaiting funding to be added to the Health Talks website. Experienced researchers and Ph.D. students under supervision are working on these modules.

### **Current activities**

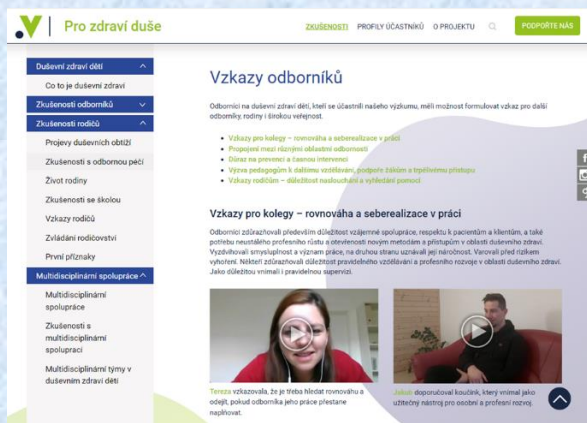
In December 2023, we published the new module about inflammatory bowel diseases: Crohn's disease and ulcerative colitis – IBD.



We also continue our work on website called Education Talks. It is a sister project of Health Talk website but the content of the website is focused specifically on the field of education. Its aim is to improve educational system in Czechia in inclusive frame, DIPEX methodology is used to collect and analyse data. In December 2023, we published a topic Mental health in children.

## Publications

Krtkova, R., Krtek, A., Pesoutova, M., Meier, Z., Tavel, P., Malinakova, K., & Trnka, R. (2023). What influences do parents perceive as supportive of school well-being and the inclusion of children with ADHD?: A qualitative study. *European Journal of Special Needs Education*, 38(2), 218–232. <https://doi.org/10.1080/08856257.2022.2050972>



Meier, Z., Gábová, K., & Tavel, P. (2023). Multidisciplinární spolupráce pro děti a

mládež s duševním onemocněním. [Multidisciplinary Collaboration for Children and Youth with Mental Illness.] *Czech & Slovak Social Work/Sociální Práce/Sociálna Práca*, 23(6).

## Project promotion and conferences

In 2023, we had the honor of hosting the Dipex meeting. Our team continues to promote the DIPEX project throughout the Czech Republic. The 4th of May we organized an online conference on multidisciplinary in mental health, where our research on mental health in children was presented.

## Germany

### Team

The team of DIPEX Germany consists of Christine Holmberg (project manager), Martina Breuning (scientific supervision), Luisa Wagenschwanz (researcher) until January 2024, Lisa Korte (researcher), Helen Frenzel (research assistant) and Anne Thier (coordination).

### Website

Since March 2023, we have been engaged in updating the modules for Chronic Pain and Cancer. The chronic pain update, which will soon be published on the website, comprises 27 new interviews. These interviews encompass individuals with various conditions, including chronic back pain, endometriosis, adenomyosis, fibromyalgia, migraine, arthrosis.

The update for the cancer module involved conducting seven interviews for the breast cancer section, and five each for colorectal and prostate cancer sections. This comprehensive update is scheduled for publication in April 2024.

In June 2023, we secured funding from the Federal Agency of Health Education for an update to the COVID-19 module. This update is scheduled for publication by the end of September.

### **New Projects**

We received funding by the Krebsallianz for a new module on “skin cancer”. The creation and publication of the module is planned for a duration of two years and three months. In addition to physical experiences, the focus should also be on psychosocial needs that have not yet been adequately addressed, e.g. stigmatization and shame due to the potential visibility of skin cancer. The main questions are as follows: What specific experiences do patients with skin cancer have? How do patients experience their disease and its consequences and how do they cope with them? 3) How do patients perceive their care and what needs do they have?

### **ORA**

In partnership with DIPEX teams from Japan, Canada, and the UK, we applied for funding for a multi-country qualitative research project titled 'Understanding Local Experiences of Global Crises: An Integrated, Multi-Country Qualitative Collaboration'. This research endeavour seeks to delve into the lived experiences and requirements of migrants/displaced individuals across four nations, aiming to provide evidence supporting refugees, caregivers, and service providers while informing policy and practices. Additionally, it aims to enhance research capacity and utilization. Furthermore, insights gleaned from integrated approaches will be translated into novel tools to facilitate multi-country responses in future global crises.

## Japan

First, we would like to thank the Czech team for their hospitality during the wonderful 2023 DI Collaborative Meeting in Hluboka nad Vltavou. Since we missed the 2022 meeting in Switzerland, it was the first in-person meeting for us in four years. It was such a lovely experience. And we are now looking forward to the next in-person meeting in Norway.

### **Website Launch**

In July 2023, we launched the Families of Children Requiring Long-term Medical Care module with 41 interviews (38 mothers and 7 fathers). The topics range from everyday medical care at home to the use of social services, schooling, the impact on the siblings, the impact on the parent’s employment, and the experience of bereavement in some cases. In September, we held a hybrid conference titled “Schooling and the post-school place-to-be for children with long-term medical care” introducing clips from the website. Among the discussants were two of the interviewed parents, a professional caregiver, a member of the Tokyo Metropolitan Education Board, and a council member of the Bunkyo Ward in Tokyo. The discussion revealed that while schools had become more inclusive in recent years, there were still not enough places in the community for persons with constant medical care after they left school.



to fund a spin-off project on the COVID experience of foreign residents in Japan.

The Heart Failure module, the Type-II Diabetes module, and the Nurses and Nursing Students with Disabilities module are still in progress. We now have a newly funded project on Perinatal Loss which will start in April.

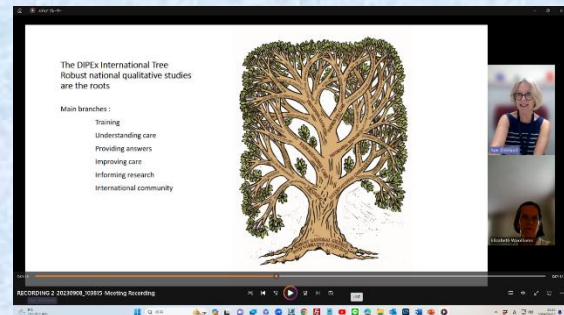
We are also engaged in a collaborative project with the University of Tokyo to create a website called “Disabled in STEMM” (<https://www.d-stemm.jp/>). We interviewed 12 researchers from around the world in the STEMM (science, technology, engineering, mathematics, and medicine) fields who have some kind of “disability” (ranging from visual or auditory impairments to physical disability and neurodiversity). Participants talked about their experience in the STEMM career, the rational accommodations they got from educational institutions and workplaces, and advised young researchers with a disability to feel more confident in seeking help and encouragement. The website was launched in the Fall of 2023 with 4 out of 12 interviews. While the website itself is in Japanese, the interviews were conducted in English, so our DI colleagues can watch and listen to their interesting stories.

### **A New Graduate Course on Health Experience Research**

Noriko Iba returned to a teaching position at St. Luke’s International University in 2022 to prepare for a new graduate course on health experience research. The course was given in the Fall semester of 2023, and for the first day of the class, Sue Ziebland kindly prepared a videotaped lecture titled “Why narrative research with patients matters.”

At the end of the course, four students gave presentations on a hypothetical research project using the patient narratives in the

DIPEX-Japan website and the data archive. One of them actually applied for data sharing to create an educational program for a brush-up course for Dementia Supporters using the narratives of people with dementia. The graduate course at SLIC will be given this Fall again.



### **Publications**

Setoyama Y, Morita N, Iba N. 2023. Experiences of Nursing Students with Disabilities in Lab and Clinical Setting Training: Secondary Analysis of Data from DIPEX-Japan “Narratives of Students with Disabilities” (in Japanese), *Journal of St. Luke's Society for Nursing Research*, 27, 11-18.

Masuda S. & Yokoyama K. 2023. Process of cancer survivors' psychological change in pain: A qualitative consideration through cancer survivors' narratives (in Japanese). *The Psychological Report of Sophia University*, 47, 33-48.

<https://digital-archives.sophia.ac.jp/repository/view/repository/20231011011>

## **Netherlands**

### **New module: Post-COVID**

The ACTION study consisted of different sub-studies that came together in a participatory action research in which care providers developed a multidisciplinary care path together with patients and other national initiatives. One of the sub-studies



focused on developing a DIPEX-module on Post COVID.

This study was funded by ZonMW. ACTION's public final conference was on April 13, 2023 in the UMC Groningen, which could also be followed via a livestream. This meeting was attended by more than 600 interested parties. The conference also contained the festive launch of the new Post COVID module. We were very happy that our colleague Nienke Verheij, who unfortunately suffers from post COVID herself, was able to launch the website. She filmed an impressive clip about her experience as a researcher working on Post COVID when she herself became ill. And she launched the website during the conference.



Figure: Nienke launching the module on Post-COVID

### Update project: psychosis

The project 'Stories of adults diagnosed with psychotic spectrum disorders on social (re)integration: development of two experience-based interventions aims to better understand experiences of adults with a psychotic spectrum disorder and learn how these experiences can contribute to improving care. The project is funded by the Dutch National Organization of Scientific Research and a collaboration of Roman Giling, Marjolijn Heerings, Hester van de Bovenkamp (Erasmus University) and Manna Alma, Andrea Fokkens (UMC Groningen) and Joyce Lamerichs

(Windesheim Zwolle). In the last year, we conducted 25 interviews with adults with psychotic experience throughout the Netherlands. We finalized the coding process and now started working on the OSOPs. Furthermore, we had the a meeting with our advisory board and presented preliminary themes for the final module. In the upcoming months we hope to finalize the module for the Dutch DIPEX website!

### Update project: experiences of menstruation

This project aims to better understand the personal experiences of menstruation and related complaints and is a collaboration between the DIPEX team and the Máxima Medical Centre. Lisa and Manna from the Dutch DIPEX team are involved and Jaklien Leemans, Peggy Geomini and Marlies Bongers from the Maxima Medical Centre. The project is funded by Fonds Alledaagse Ziekten (Fund Everyday Illnesses) and co-funded by the Innovation Fund of Máxima Medical Centre.

In December 2023, the last interview was conducted. A total of 33 stories of menstrual experiences are collected. Within these 33 stories there is a wide variety of different experiences. The stories contain experiences from varying diagnoses (e.g. endometriosis, fibroids, heavy menstrual bleeding), from varying ethnic and cultural backgrounds (e.g. Syrian, Moroccan, Cuban, Polish, Surinam) and from two trans men. It has been quite challenging to recruit and suffice to maximum variation sampling. Currently we are analysing all interview data and aim to have developed the module by the summer. We plan to evaluate the module using the eHealth Impact Questionnaire (eHIQ) in September this year before launching the module.

### Meeting arts-based research

On Friday February 2nd, researchers from DIPEX Netherland based at University

Medical Center Groningen, at Erasmus University Rotterdam, and Windesheim University of Applied Sciences, came together in Zwolle for a daylong meeting in which they presented their work that involved different strains of arts-based research. The goal of the meeting was also to share and develop new ideas for collaboration in the Netherlands. The idea is to make this into a recurrent event as it offers valuable time and opportunity for focussed discussion. On this day, we discussed integrating arts-based methods into some of our current grant applications, how to strengthen our arguments for such research, working with mixed methods and methodological rigour. We also developed plans to collaborate in an upcoming, national bid on science communication, which allows us to flesh out our shared perspective on participatory research in our DIPEX work.



*Figure: An impression of different arts-based methods to elicit the perspective of clients and their next of kin, as part of a project on assisted living. (Beschermd Wonen in Beweging)*



*Figure: The Slovak DIPEX team visited the Dutch DIPEX team in Groningen*

### Visits from DIPEX team Slovakia

In the past year, the Slovak DIPEX team visited us twice. Our first meeting was in June 2023, when we discussed potential collaboration. Recently, in January, the Slovak team visited Groningen for a few days. During this day we exchanged experiences. In addition, Manna and Andrea provided a training in coding, OSOP, writing thematic summaries and development of the website.

We look back on a very successful and inspiring meeting in the Czech Republic. And we hope to see you all again in Norway!

Greetings from Manna Alma, Roman Giling, Marjolijn Heerings, Joyce Lamerichs and Lisa Zuidema



*Figure: The Dutch DIPEX team in the Czech Republic*

### Relevant papers

Greaves-Lord, K., Alma, M., de Graaff, B., Landsman, J., van der Weide, K., Jagersma, G., Beskers, T., Wubs, M., Mandemaker, H., van Daalen, E., van der Linde, J.,

Stapert, A. F., Bekius, J., Piening, S., Landlust, A., & van Balkom, I. (2023). Clinical stance on response initiation in autistic adults: co-creating an integrative approach based on theory and lived experiences to act from language, via motor movement to wellbeing. *Frontiers in Psychology*.

<https://doi.org/10.3389/fpsyg.2023.1229596>

more about the venue:  
<https://sommenroy.no/>

## Slovakia

### The 2023 year was exceptional!

The Slovak team has been very productive and is happy to announce many exciting news.



*Daniela, Jaroslava, Iva, Lucia, Zuzana & Janko*

### Team

We welcomed a new member to our team, Janko Hlodák. He is a PhD student in Health Psychology and at the same time works as a psychologist in a counselling centre for children and adolescents. His scientific work is focused on sleep disorders and narcolepsy. Janko quickly adapted to us and is a great addition to our team.



*Janko Hlodák*

## Norway



*Team Norway work meeting 2024  
Marianne T, Sigrid, Marianne L*

### Welcome to our new team member

This year we are happy to welcome our new team member Marianne Larssen who started her PhD study this March. Her project title is “Sámi men’s stories of suicidality and the roads to recovery” and she has designed a qualitative study based in the DIPEX methodology, to be started during the year.

Welcome to Norway!

Also, we are of course very happy to start the planning of the DIPEX 2025 meeting, which will take place in Tromsø, Norway.

We will go to a conference hotel approximately 45 minutes’ drive from the airport, follow this link if you want to read

### Current activities

The Slovak team has started preparing two new modules: Module on Narcolepsy led by our colleague Janko Hlodák and Module on Dialyzed patients led by our colleague Iva Skoumalová. Both modules are already about halfway through and should be launched next year. Thus, Slovakia is currently working on 4 modules altogether, including two modules on system of care for adolescents with mental health problems and their parents which we started preparing last year.



*Zuzana and Iva*



*Lucia and Janko*

Together with DIPEX NL and DIPEX CH we also participated in the consortia which prepared Horizon grant proposal related to infertility and IVF treatment within European Commission call HEALTH. This was unfortunately not successful; however, our cooperation does not end, and we will try again in the next round. Finally, we also submitted a project proposal within the national scientific grant scheme for the development of a new module related to childbirth experiences, which we want to start preparing in 2025, if we get funding.

### Meetings and events

In September, we attended DIPEX International Annual Meeting in the Czech Republic. We had a wonderful opportunity to present our projects, to exchange knowledge and experiences and spend a magic moments within our DIPEX International family.

Best wishes to all DI members from the DIPEX Slovakia team! See you soon!

## Spain

### New Projects

We are completing the **DIPEX Covid-19** module, which will be launched before the end of 2024. This project, funded by the Spanish Ministry of Science (Health Institute Carlos III), includes an arts-based knowledge transformation. We are working with a multidisciplinary team, including fine arts and designing a documentary format to present international results that contribute to historical memory, relate to patients, families, and healthcare providers, and pay honour to the lived experience of this pandemic.

We have almost completed the data collection for the **Intimate partner gender violence** module, which received a small

two-year grant from a Regional Funding Health Research Call. Interestingly, data saturation was achieved before being expected. According to our plans, this module will be available by the end of 2024.

At the end of the year 2023, we achieved funding from the Spanish Ministry of Equity to develop a short film based on the results of the Intimate partner gender violence to disseminate information about the signs to detect partner gender violence. This project has allowed us to create an animated short film and didactic material in comic format to use in education centres. This project is part of the doctoral dissertation of Jessica García.



The following new project we are working on aims to create educational material for health care providers based on DIPEX

modules as training for person-centred care and enhancing humanized care in Spain. This project will be Elisa Torres's doctoral dissertation. She was one of our medical students who did her Final Degree Project with DIPEX COVID-19 data and now continues with our team as an internal medical resident of Family Medicine.



### **Knowledge Translation and Dissemination**

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

Related to this project, we have worked on a documentary short film based on inherited retinal Dystrophies patient experiences working with the Canary Islands Health Care Services and Patient Association (Available at: <https://youtu.be/Y9r5Ww7NZ-s>)

Currently, we are working with DIPEX international material related to the DIPEX Covid-19 module to prepare a short film based on testimonies from different countries.

We presented at the XXXII Communication and Health Conference of the Spanish Society of Family and Community Physicians (Zaragoza, 23-25<sup>th</sup> March 2023) two papers related to DIPEX and MUSA experience as useful tools for health communication.



### Other News

We are pleased with the international collaboration and learning to publish shared papers. We hope we can continue with the shared module related to Ukrainian refugees.

Mario Martín Labrador, who presented at our International meeting the advances on this project related to the experience of healthcare providers and patients who suffered from COVID-19 during labour,

has now organized his visit to Oxford University and Kyoto University. These stays will be an incredible experience for him and, in fact, for all of us.



We are pleased to introduce Alejandra Méndez, who is part of DIPEX Spain through a national funding based on European funds called INVESTIGO, for one year.



We were delighted to attend the DI meeting in 2023:



Moreover, we expect to see you all again in Norway next time!

## Switzerland



*Group photo DIPEX Switzerland – from the left row in the back to the row in front: Dominik Bolliger, Nikola Biller-Andorno, Giovanni Spitale, Andrea Glässel, Beatrix Göcking, Andrea Radvanszky, Sebastian Wäscher - Bettina Schwind, Corine Mouton-Dorey are not pictured.*

### Dear Colleagues,

The last year, 2023 was characterized by a wide range of tasks for DIPEX Switzerland. We continued to develop DIPEX as an overall project in various areas and networks. Some of the highlights and milestones are briefly presented here:

- Andrea Radvanszky has completed the module for young people with haemato-oncological diseases and is currently working on the website content. We are looking forward to this important module, experiences, and insights.
- At the end of the year, we completed a master thesis on a secondary analysis using DIPEX data and focus groups with healthcare professionals from the chronic pain module by Bettina Schwind and in collaboration with Andrea Glässel. It is great to see how practical experience provides

information about the care situation and to strengthen collaborations with partners in academia and practice.

- In 2023, we submitted five research proposals in which DIPEX played a central role in the research design of different topics. In one proposal, we were part of the submitting consortium from the DIPEX network. Unfortunately, three of the applications were not approved. One Swiss National Science Foundation application was successful in connection with DIPEX by focusing on ethics and education; another application we are still awaiting a decision.

June 2023, Nina Streeck and Michael Coors organized the conference "Caring for the Orphans: Ethical Issues in the Context of Rare Diseases" as part of the University of Zurich's research priority program, "ITINERARE: Innovative Therapies in Rare Diseases." The two-day event was thoroughly organized by connecting experts in rare disease ethics from various countries, including the USA, Canada, Italy, Switzerland, Sweden, and Germany. The conference featured thoughtfully curated speakers and discussions, encompassing a broad spectrum of current topics in the field of rare diseases. The presentations offered insights into the diverse challenges and advancements currently discussed in the field. Throughout the conference, two members from DIPEX International shared valuable insights into their ongoing work. Rachel Grob presented: "Diagnostic Information and Uncertainty in the Newborn Period: Qualitative Dimensions of 'Families' Experiences with Novel Technologies." Later that day, Sebastian Wäscher delivered a talk titled: "If You Hear It from a Doctor, You Internalize It: Medical Gaslighting in the

Field of Rare Diseases – Insights from a Qualitative Interview Study." Both presentations contributed valuable perspectives to the ongoing ethical discussions in rare diseases, emphasizing the value of qualitative research in understanding the multifaceted experiences of patients.

We are delighted to share the latest progress at the intersection of patient narratives research and healthcare informatics. Giovanni's current endeavor focuses on the pioneering integration of Artificial Intelligence (AI) with patient data derived from our DIPEX repository.

The ambition to craft AI-powered synthetic patients is at the heart of Giovanni's work. Giovanni endeavors to distill intricate patient narratives into concise yet comprehensive descriptions by harnessing the power of open-source LLMs, facilitating enhanced understanding and decision-making for healthcare practitioners. This interdisciplinary approach underscores the synergistic potential of AI and natural language processing in healthcare contexts. This strategic utilization of cutting-edge local open-source models ensures the ethical handling of personal sensitive data, thereby addressing concerns surrounding data privacy and security.

The implications extend far beyond theoretical realms. Beyond medical education, the envisioned AI-enabled systems promise to enhance clinical decision support, optimize resource allocation, and ultimately improve patient outcomes.

We are thrilled to announce the publication of a methods paper by the Swiss DIPEX team, which outlines a best-practice approach to harnessing patient narratives as invaluable insights into healthcare

experiences. In recent years, patient narratives have emerged as a cornerstone in healthcare research, offering profound insights that complement traditional clinical data.

The paper delves into the meticulous process of collecting, analyzing, and utilizing patient narratives, drawing upon a wealth of current literature and the rich experience from developing the Swiss Database of Individual Patient Experiences (DIPEX). The paper provides a comprehensive overview of the Swiss approach. It elucidates the potential uses and benefits of patient narratives, from enhancing healthcare practice and empowering patients and caregivers to fostering improved communication structures within healthcare settings. Additionally, it highlights the invaluable contribution of patient narratives to medical teaching and learning, enriching the educational landscape with real-world insights.

This publication marks a significant milestone in advancing our understanding and utilization of patient narratives in healthcare research and practice, offering actionable insights and methodologies to harness the transformative power of patient narratives.

### **Published papers**

Spitale G, Glässer A, Tyebally-Fang M, Mouton Dorey C, Biller-Andorno N. (2023). Patient narratives - a still undervalued resource for healthcare improvement. *Swiss Med Wkly.* 30;153:40022. doi: 10.57187/smw.2023.40022. PMID: 36787439.

Göcking B, Biller-Andorno N, Brandi G, Gloeckler S, Glässer A. Aneurysmal Subarachnoid Hemorrhage and Clinical



Decision-Making: A Qualitative Pilot Study Exploring Perspectives of Those Directly Affected, Their Next of Kin, and Treating Clinicians. (2023). *Int J Environ Res Public Health*.11;20(4):3187. doi: 10.3390/ijerph20043187. PMID: 36833886; PMCID: PMC9958564.

## UK

Warm greetings from the UK!

A highlight for the year was the Collaborators meeting in České Budějovice. It was an absolute joy to meet up with our wonderful colleagues. A huge thanks to our Czech colleagues for pulling off such an excellent meeting in a superb location. We were delighted that some past and present members of MS&HERG were able to attend again (including Lisa Hinton, Ruth Sanders, Sharon Dixon, Anna Dowrick, Bakita Kasadha, Tori Ford, Cervantée Wild) as well as our University of Stirling colleague, Alice MacLean. Several of us stopped off for an overnight or weekend in Prague or Berlin on the way there or back, including a delightful evening at the Prague ballet with the team from Japan. We are looking forward to meeting online in 2024 and an arctic adventure in Norway in 2025.

We have been delighted to work on a grant submitted to the Open Research Area for Social Sciences call with colleagues from Canada, Germany and Japan. This project will develop efficient, timely, equitable and effective approaches to multi-country qualitative research collaboration at times of global crises. We will explore the lived experiences and needs of migrants/displaced persons in four countries to contribute evidence to support other refugees, carers and providers, and inform policy and practice, while building capacity for research and research use.

Several of our studies are now complete and either published or awaiting publication:

### Completed

Urogynaecological conditions (PI Abi McNiven)

Burns (Christia Huntington's doctoral research)

Self-funders (PI Kate Baxter, York University) Published on socialcaretalk.org

Loneliness (with AEBCD in social care) (PI Sara Ryan, now Manchester Met University) near completion

### Ongoing

Dementia and dementia carers (Suzanne Ii) – to be published 2025

Knee replacements in the context of comorbidities (co PI Abi McNiven) – to be published 2025

Painful periods (Sharon Dixon's doctoral research) – to be published 2025

Care Leavers (including refugees/migrants) Suzanne Ii – to be published 2025

Stillbirth (Danya Bakhbaki's doctoral research) – TBC

Mesh- breast reconstruction (Rachel Rolph's doctoral research)

High blood pressure in pregnancy (Layla Lavalley's doctoral research)

### New publications since last newsletter:

Kasadha, B., Tariq, S., Freeman-Romilly, N. et al. "We decided together": a qualitative study about women with HIV navigating infant-feeding decisions with the father of their children. *BMC Pregnancy Childbirth* **24**, 41 (2024). <https://doi.org/10.1186/s12884-023-06198-w>

Rai, T., Kasadha, B., Tariq, S., Keating, S., Hinton, L., Namiba, A., Pope, C. Infant feeding as a transgressive practice in the context of HIV in the UK: A qualitative interview study, *Women's Studies International Forum* **101**,

2023, 102834,  
<https://doi.org/10.1016/j.wsif.2023.102834>.

Kasadha B, Tariq S, Nyatsanza F, Freeman-Romilly N, Namiba A, Rai T. Stakeholder engagement is essential to maximise the impact of research on infant feeding in the context of HIV. *Therapeutic Advances in Infectious Disease*. 2021;8. <https://journals.sagepub.com/doi/10.1177/20499361211057970>

Dowrick, A., Qureshi, K., & Rai, T. (2024) Negotiating un/sanitary citizenship: the reception of UK government COVID-19 public health messaging by racialised people highly exposed to infection, *Anthropology & Medicine*, <https://doi.org/10.1080/13648470.2023.2274710>

Qureshi, K., Dowrick, A. & Rai, T. (2023). Immunisations and imagining imperilled fertility: Women's trials of COVID-19 vaccines and reproductive/citizenship transgressions in pandemic times. *Women's Studies International Forum* 100, 2023, 102739, <https://doi.org/10.1016/j.wsif.2023.102739>.

MacLean A, Wild C, Hunt K, et al. (2023). Impact of Long Covid on the school experiences of children and young people: a qualitative study. *BMJ Open* 13:e075756. doi: 10.1136/bmjopen-2023-075756

Maclean, A., Hunt, K., Brown, A., et al. (2022). Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy. *SSM - Qualitative Research in Health* 100207. <https://doi.org/https://doi.org/10.1016/j.ssmqr.2022.100207>



*DIPEX Czech Republic Bikes and Beers Team*



*British-Brazil diplomatic relations*



*DIPEX Czech Republic Swimming Team*

## United States

Greetings from the US!

Over the past year, our US Health Experiences Research Network (HERN) steering committee gathered in person twice – in Portland, Oregon in January 2023

and in Baltimore, MD in February 2024. The focus of our recent retreat in Baltimore was to reflect on our growth and accomplishments as a network and to set priorities for the next 5 years. It was both hard work and a lot of fun. Since we are so spread out geographically, we always treasure spend time in person together as a steering committee (the attached picture was taken at a restaurant in downtown Baltimore).



As our network has grown, we have continued to train new researchers and have many modules, pilot projects, and catalyst films in the field or in various stages of production. Some highlights are listed below.

### Learning and Training

Since 2019, the University of New Mexico's Clinical and Translational Science Center has hosted annual HERN trainings, in partnership with HERN faculty from several institutions, with support from the National Center for Advancing Translational Sciences, National Institutes of Health (grant number UL1TR001449). As of 2024, we have welcomed 183 trainees from 29 institutions, 14 states and Washington, DC, and three countries. We currently offer two training sessions. Trainings are offered each year and alternate between 1.0 and 2.0. The next 2.0 training will occur in May 2025. Please contact [HERNTraining@salud.unm.edu](mailto:HERNTraining@salud.unm.edu)

for more information or to receive updates about upcoming trainings.

- 1.0 Introduction to HERN and DIPEX: Offered virtually; provides an introduction to HERN and DIPEX methodology;
- 2.0 Advanced HERN Training: Offered in person in Albuquerque, New Mexico; provides more in-depth training and skill building in the DIPEX methodology for those who have completed the 1.0 training.

In addition, we continue to host bi-monthly Learning Network sessions for our network of researchers across the US both to build community and to provide ongoing learning and training. These sessions are virtual and open to anyone who has taken part in a HERN or HERG training.



*Group photo from HERN 1.0 Training in February 2024*

### Publications:

Beeler, D., Christensen, V., Parker, K., Cottrell, E. "The place it puts us in emotionally and relationally with our child, it's damaging": understanding the real-world psychosocial needs of caregivers of childhood cancer survivors. *Journal of Cancer Survivorship* (2023). <https://doi.org/10.1007/s11764-23-01461-7>

Evered, J.A., LaJeunesse, A., Wynn, M., Mrig, E., Schlesinger, M., & Grob, R. (2023). Gaps in benefits, awareness, and

comprehension that leave those with long COVID vulnerable. Chronic illness, 17423953231210117. Advance online publication. <https://doi.org/10.1177/1742353231210117>

Grob, R., Van Gorp, S., & Evered, J. A. (2023). "You have to trust yourself": The Overlooked Role of Self-Trust in Coping with Chronic Illness. The Hastings Center report, 53 Suppl 2, S39–S45. <https://doi.org/10.1002/hast.1522>

Parker K, Christensen V, Lindemulder S, Chan, LHK, Saxton L, Cottrell E. Family perspectives on the transition from active treatment to survivorship for children with cancer. Pediatric Blood Cancer.2023; e30490. <https://doi.org/10.1002/pbc.30490>

Smith, K. C., Schlesinger, M., Warne, E., Wise, M., & Grob, R. (2023). The familial canopy as thought space for meaning making, emotional calibration and planful action around inherited cancer risk. SSM- Qualitative Research in Health, 3, 100282.

### **Presentations:**

Evered, J., Davis, S., Patrick, B., Maske, C., Schrage, S., Park, L., Henningfield, M., Yuroff, A., Grob, R. (2024, January 19). Learning from patients and communities about long COVID: A pilot intervention in primary care [Poster]. Institute for Clinical and Translational Research Day, University of Wisconsin Madison, Madison, WI, United States.

Cottrell, E. "Elevating Veterans' Voices: An Innovative Approach for Understanding Veterans' Experiences with Firearm Injuries," Oral presentation, Society for Advancement of Violence and Injury Research conference, April 17-19, 2023, Denver, CO.

Lafferty, M. "Unintentional Firearm Injuries among Veterans: A Mixed-Methods Approach to Understand Frequency and Context." Presentation, 2023 National Research Conference for the Prevention of Firearm-Related Harms, Nov. 1-3, 2023, Chicago, IL.

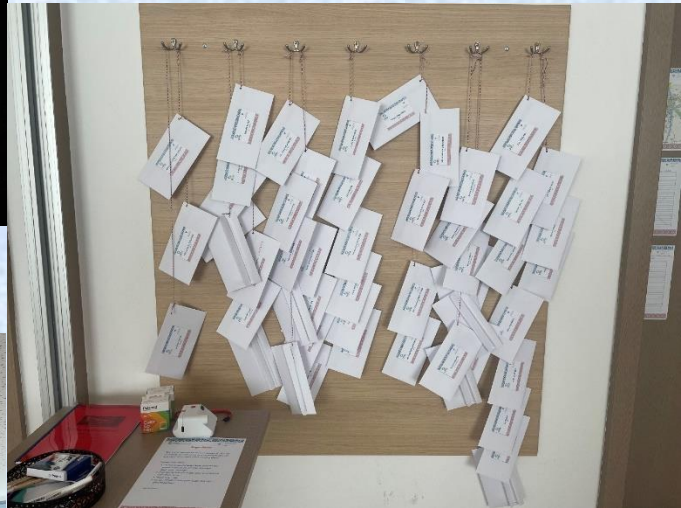
Grob, R. Trust's Tributaries: Patients' and Families' Experiences on the Waterways. Invited presenter; Who Do You Trust? Shifting Trust in Healthcare Fall Ethics Conference; Merriter Health System, Virtual, November 3, 2023.

## The DIPEx Charity

Dear All,

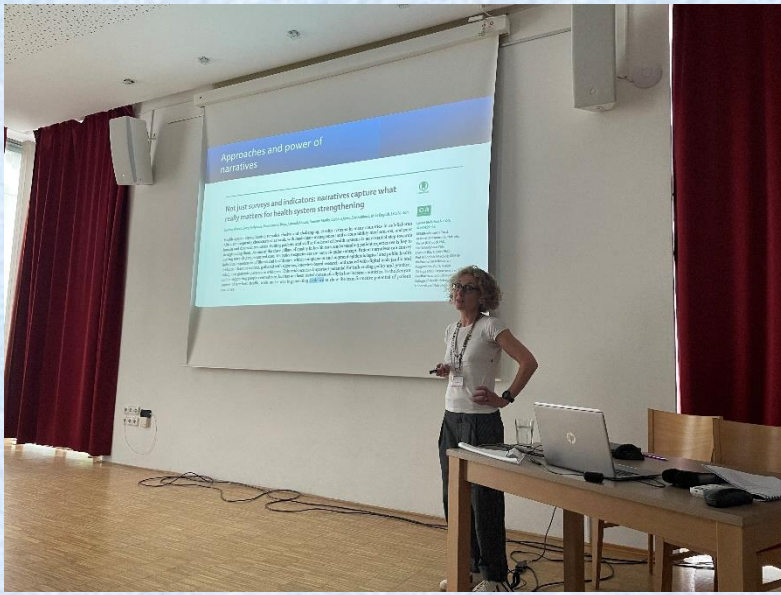
This last year has been a very busy one for in the Dipex Charity team. In addition to the brilliant new modules we added with MS&HERG, we've been working to get the redesigned [healthtalk.org](https://healthtalk.org) and [socialcaretalk.org](https://socialcaretalk.org) launched. This has been my 3rd redesign and Adam's 4th since working for the charity and it never ceases to amaze us how difficult it is to migrate 20 years plus of complex website data to a new platform. However, we are thrilled with the new websites which both have beautiful new colour schemes and new functionality. We hope you like it too.

Reminiscing DI meeting 2023  
18 – 21 September, the Czech Republic

















# INFLAMMATORY BOWEL DISEASE

**"Tell me your story with Inflammatory Bowel Disease from the first symptoms to the present day."**

Hana BEDNARIKOVA, Kristyna CABOVA  
Olomouc University Social Health Institute, CZ

**INTRODUCTION**  
Inflammatory Bowel Diseases (IBD) encompass chronic inflammatory intestinal disorders, including ulcerative colitis (UC) and Crohn's disease (CD). These conditions significantly affect patients' lives due to persistent symptoms such as pain, diarrhea, urgent bowel movements, incontinence, blood and mucus in stools, flatulence, weight loss, and fatigue.

**WHAT HAS BEEN DONE SO FAR**  
Collection of 36 interviews, their transcripts and analysis. All actions have been consulted with the Advisory Panel and approved by the Ethics Committee. Thematic analysis of the interviews revealed several important themes. The first scientific outputs were devoted to the topics of sexuality and family planning, as well as the messages that the participants have for their doctors.

**Participants**  
IBD: 20, UC: 18, CD: 19

**Diagnosis**  
IBD: 11, UC: 7, CD: 4

**Age at diagnosis**  
20-29: 13, 30-39: 20, 40-49: 5, 50-59: 3, 60-69: 5

**RESEARCH TIDBITS AND EXPERIENCES**

Participants were recruited either at patient conferences, through social networks, through contacts with people from patient organisations or through our website. Participants were engaged and many were very educated and knowledgeable about their own disease. Some patients have lived with IBD for many years, there we have noticed that healthcare attitude and awareness of the disease has improved over the years. For newly diagnosed patients, the process of diagnosis was mostly much shorter. Despite a disease characterized by chronic fatigue, most patients tried to work with full effort, in very severe cases in a limited mode.

Humour - very specific - related to symptoms such as flatulence. Incontinence - was a very common concomitant coping mechanism. Motto: Don't shit yourself! Just because you have IBD!

These participants were very willing to talk about their illness because they liked the concept of their story helping someone else.

In the interviews that took place at the participants' homes, it was interesting to note that they all had beautiful toilets :-)

It's nice to find out that it's a common disease.

To hear from someone during those rougher periods that you're not alone in it might be encouraging.

For a person who finds out they have Crohn's and reads the experiences of others, it's great.

Because every piece of advice is actually very valuable, right?

I'm here, because I really liked the idea, for those people to know and hear the stories of other people. That they aren't alone in it.

We are very grateful to organisations Patients' IBD and ILCO for their support in recruiting participants and all the patients who kindly gave their time to participate in the study.

**[DI2023]**  
Realizations from Creating a DIPEX Module on the Families of Children Requiring Constant Medical Care

Ryoko HATANAKA, the University of Tokyo, SHOBI University, JAPAN  
ryoko.hatanaka.kato@gmail.com  
Rika Sato Sakuma, DIPEX-JAPAN

This study was supported by a Toyota Foundation Research Grant(2020.4~2023.3) and Grants-in-Aid for Scientific Research by JSPS(2020.4~)

**Background and Summary**  
It is estimated that about 20,000 children in Japan require constant medical care, such as ventilators, gastrostomy, and sputum aspiration through tracheostomy, in their daily lives. Parents without medical training must provide advanced medical care every day, and face various problems, such as a lack of social support, imposed gender roles, and to continue working, because they need to transport their child to and from school every day, and sometimes need to accompany the child throughout school hours. They are also concerned that their children will not have a place to stay after they graduate from public school. We interviewed 42 family members (34 mothers and 8 fathers), in their 30s to 50s who have or had a child requiring constant medical care. The website was launched in July 2023 (https://www.dipecx.jp/med-care-child/).

We noticed a significant difference between this project and other projects that DIPEX-Japan has worked on so far. Interviewing parents about their children's disability requires completely different considerations from interviewing patients about their own illness experiences. For example, expressions such as "Why is this happening to me?" are likely to have very different meanings when speaking about one's illness in contrast to when talking about one's child. One interviewee later regretted the fact that he confessed the pain of not being able to accept his child wholeheartedly as a parent.

**Participant demographics**

Number of interviewees by age	Age of the child	Medical Care (overlapping)
Mother 30s 11	0-2 yold 7	Tracheostomy 25
40s 15	3-5 yold 9	Ventilator 20
50s 7	6-9 yold 6	Home oxygen therapy 3
Father 30s 1	10-12yold 4	Sputum aspiration 30
40s 5	13-15yold 6	Nasal tube feeding 9
50s 2	16-19yold 6	Gastrostomy 27
	Over 20yold 1	Other 12

**Topics**

- Becoming a parent of a child with medical care
- Overview of the children with constant medical care
- Awareness of disability leading to medical care
- Acceptance of the child's disabilities and illnesses
- Recognition of the need for medical care
- Living with Medical Care
  - Preparation of the home environment
  - Daily life and care
  - Going out and moving around
  - Involvement of neighbors and supporters
  - Preparing and coping with emergencies and disaster
- Social services and resources
  - Public and Private Services
  - Access to Services and Information
  - School (enrollment)
  - Enrollment consultation and school selection
  - Drop-offs and pickups for schooling
  - Parent attendance at school
  - Learning at school
- Family Life
  - Division of roles among the family members
  - Impact of siblings
  - Parent's work-life
  - Private time
- Children's Life
  - Children's favorite things and play
  - Thoughts on the growth and future of children
  - Foreword to children

**Members and Timeline**

**Project Member**  
Ryoko Hatanaka(Law)  
Kyoko Kobayashi(Nursing)  
Kaori Nishigaki(Nursing)  
Rika Fukusami(Nursing)  
Shota Kakazu(Nursing)  
Rika S. Sato (Sociology)  
Noriko Ibe(Nursing)

**Timeline**  
2018 Two NPOs approached DIP-J to raise social awareness of the lives of families of children with constant medical care  
Winter 2018 Project started by DIP-J and St. Luke's International University's Department of Pediatric Nursing  
Mar. 2019 A Kick-off Event "Mom's Story is Not Just Complaints"  
Sep. 2019 Got a Research Grant from The Yuami Memorial Foundation for Home Health Care  
Nov. 2019 The first interview for the pilot study was conducted.  
Mar. 2020 Onset of the Covid-19 pandemic  
April 2020 The full-scale project began with a Toyota Foundation research grant  
Sep. 2020 Online Symposium  
June 2021 The Act on the Support of Children Requiring Constant Medical Care and Their Families was enacted.  
42 interviews completed.  
Mar. 2023 Website Launch  
Sep. 2023 Public Symposium  
Fall 2023 Website scheduled for completion.  
The 2025 Website is scheduled for an update

**DIPEX COLLABORATIVE MEETING CZECH REPUBLIC**  
2023.18-21. September, 2023

## Collaborative ideas for DIPEX International in Aotearoa New Zealand

**Kōrero Mai | Speak to me**

Aotearoa has a strong tradition of **oral storytelling** that aligns well with the DIPEX approach of prioritising participant voice

Under the **Treaty of Waitangi** researchers have a responsibility to ensure their research is **responsive to Māori**

Recent **health system reform** with opportunities for service improvements and evaluation

Two **medical schools** plus regional teaching hospitals throughout the country

Opportunity to experiment with best **content output**: video, podcasting, social media etc

Opportunity for trans-Tasman **collaboration and mentorship**

**5.1 million people on a landmass that is 10% larger than the UK**

**17% Māori (Indigenous people of NZ)**

**Publicly funded health system**

**Major health system reform**

**High levels of childhood diseases of poverty (e.g. rheumatic fever, measles, respiratory disease)**

**High rates of NCDs**

**Health inequity**

**Responsibility to our Pacific neighbours (climate refugee health)**

**How can we apply DIPEX principles and methodology in a way that is appropriate to the NZ context?**

**Pātai | Questions**

- How will we reconcile a maximum variation sample with adequate sampling of Māori experience?
- How will we fund the website/resource?
- Will people want to be filmed with a population of only 5 million?
- How can DIPEX benefit from an Indigenous worldview and ways of knowledge construction?

**Understand patient and whānau experiences of health and the health system**

**Produce a public-facing multimedia resource for patients, whānau, clinicians, & policy makers**

**Use that information in clinical training and service improvement**

**Cross-country comparison with our Pacific & international neighbours**

**THE PARENTAL EXPERIENCES WITH CHILDREN WITH MENTAL HEALTH ISSUES**

Nika Totová [1], Kristýn Anna Cerníková [2]

1. Palacky University, Olomouc University Social Health Institute  
2. Palacky University, Department of Christian Education

**BACKGROUND**

Parents, teachers, and healthcare professionals are key in identifying and managing children's mental health. A safe space needs to be provided for children to express themselves without judgment or stigma. Early diagnosis and proper treatment greatly impact children's well-being.

**METHODS**

In this qualitative study, we conducted semi-structured interviews with audio recording and verbatim transcription. DIPEX methodology was modified due to resource limitations. Thematic analysis with open coding in NVivo 2000 was used to identify key themes.

**PARTICIPANTS**

Parents of children with mental health disorders. Fourteen (n=14) respondents were parents of children with mental disorders, with a mean age of 41.3 (Med 43.5; MIN 23, MAX 59). Nineteen (n=19) respondents were professionals (teachers, and healthcare professionals etc.), with a mean age of 31.8 (Med 40; MIN 23, MAX 59).

**OUTPUTS**

The article, "Psychologists' Preparedness for Children's Mental Health: A Qualitative Study," is almost ready for submission. A website, [hovoryzdelavani.cz](http://hovoryzdelavani.cz), is also being prepared to address educational needs, derived from [hovoryzdravi.cz](http://hovoryzdravi.cz). Other potential publication topics e.i. education experiences, mental health perceptions, coping strategies, and the readiness of helping professions.

**CONCLUSIONS**

Our efforts are directed towards acquiring resources and subsequently gathering data for the complete DIPEX module. If someone is engaged in a similar topic, we are open to collaborating on joint publications.

**Defining primary dysmenorrhoea in research and academic discourse; why discrepancies matter**

Sharon Dixon<sup>1</sup>, Claire Duddy<sup>2</sup>, Neda Taghinejadi<sup>1</sup>, Katy Vincent<sup>1</sup>, Sue Ziebland<sup>1</sup>

<sup>1</sup>Nuffield Department of Primary Care Health Sciences, University of Oxford  
<sup>2</sup>Nuffield Department of Women's and Reproductive Health, University of Oxford.

**Background:**

- Dysmenorrhoea affects up to 91% of teenagers who menstruate
- Dysmenorrhoea is categorised into primary dysmenorrhoea (no identified underlying pelvic pathology) and secondary dysmenorrhoea (dysmenorrhoea in association with pelvic pathology). Disagreement between these is a public, clinical and academic challenge
- Of us worry about 'folding the uncertainty envelope' in differentiation between 'idiopathic primary and secondary dysmenorrhoea'
- Whilst categorisation is often decided as 'straightforward', we suggest that delays in diagnosis of the most common cause of adolescent secondary dysmenorrhoea (endometriosis) highlight the complexity of this task.

**Aim:**

To describe how primary dysmenorrhoea is represented in discourse about adolescent dysmenorrhoea, and consider why inconsistencies matter for practice

**Method:**

- Narrative mixed-methods synthesis exploring adolescent dysmenorrhoea in community health settings, focussed on generating resources for UK primary care including considering areas of uncertainty and research or service needs
- Protocol and search strategy: PRISMA 2020 (2020)
- We have included 322 full text papers in this narrative synthesis
- We conducted a sub-group analysis of all included papers reporting empirical evidence about primary dysmenorrhoea, enumerating how this was operationalised in research practice
- The selection and screening process is summarised below:

**Findings:**

- We identified no studies conducted with adolescents with a primary care or community health settings
- Throughout the review, we identify discrepancies in language and process, relevant to the process of differentiating between primary and secondary dysmenorrhoea, including:
  - The time interval between menopause and onset of pain and the onset of dysmenorrhoea being primary or secondary
  - Primary dysmenorrhoea and cyclic regularity (often aligned with ovulation or ovulatory cycles)
  - Responses to therapeutic interventions with treatments such as non-steroidal anti-inflammatory and hormonal contraception and the likelihood of developing pathology (mostly endometriosis)
- There is a lack of evidence where community care settings outline what to do if a therapeutic trial is ineffective in individual settings
- The 83 studies which report empirical evidence about primary dysmenorrhoea utilise a range of approaches to differentiating primary and secondary dysmenorrhoea, characterised below:

**Conclusions and impact**

- These inconsistencies and limitations of methodological approaches for defining primary dysmenorrhoea in empirical evidence suggest that most studies report unexamined dysmenorrhoea
- This influences understanding and expectations about characteristics of typical primary dysmenorrhoea
- Alongside uncertainty about the general prevalence of endometriosis, this creates structural uncertainty regarding the process of differentiating between primary and secondary dysmenorrhoea, evident internationally

**Why this matters:**

- Diagnosis is defined as the making of a judgment about the exact character of a disease or other problem<sup>1</sup> and refers to both the process and the endpoint of clinical reasoning
- Diagnosis translates a syndrome (or frequently even-limited sensations) to something that appears understood, measurable (symptoms and associated features)
- Seen through this lens, we contend that primary dysmenorrhoea functions as a diagnosis (a condition with a known cause and understood aetiology), in contrast with dysmenorrhoea, which is represented as a symptom
- We argue that by conflating the symptom (dysmenorrhoea) with a diagnosis (primary dysmenorrhoea), underpinning by uncertain inference, risks constraining clinical reasoning and could contribute to delays in diagnosis

**Contact:**  
Sharon Dixon, [sd1@nuffield.ox.ac.uk](mailto:sd1@nuffield.ox.ac.uk)

**Connecting, Contributing, and Creating Visibility with our DIPEX International Site on LinkedIn**

DIPEX International  
Database of Individual Patient Experiences  
Health and Human Services - WITNEY · 42 followers · 6 employees

**JOIN US**

Join us on the DIPEX International LinkedIn site, where the world's largest professional network comes to life

LinkedIn, a Microsoft-backed platform with over 850 million members spanning 200+ countries, offers a global stage for connection and collaboration.

Our LinkedIn site offers us the opportunity to strengthen our successful international network. We will expand our professional reach, amplify project awareness, and foster knowledge exchange.

Whether you prefer the app or website, LinkedIn offers accessibility, allowing you to share events, informal networks, initiate individual profiles, and impactful content. Sign up to share on our initiatives as we share news and promote meaningful interactions.

Follow us on LinkedIn and become part of a dynamic community. You are also welcome to share the link with interested parties to spread the word about DIPEX work.

Be creative and design your post for a lively DIPEX International site

We are currently looking for one to two administrative per member country to post country-specific news. At this time, our DIPEX profiles is sponsored by nine members from five countries (Germany, Slovakia, the USA, Switzerland, and the Netherlands).

It would be great to include admins from all members of the DIPEX society. We are looking for admins from Australia, Brazil, Canada, the Czech Republic, Japan, the Republic of Korea, Norway, Spain, and the United Kingdom.

When each country shares around four posts yearly, we can increase our visibility internationally. In addition, we learn much more from each other and establish lively exchange.

Visitors on DIPEX International site last year:

Impression seen by LinkedIn members:

Swift Admin Team

Empowering Voices, Sharing Experiences: DIPEX - Your Health, Your Story.









