# ANNUAL REPORT

2021/22

July 1, 2022



## HUMAN HEALTH PROJECT

Human Health Project's (HHP) foundation is built upon peer-to-peer holistic health information, education, and support. Through our programs, our objective is to empower individuals locally and globally to manage their health.



## ABOUT HHP

#### Our Vision

To be the leading global resource for peer-to-peer holistic health information, education, and support. We envision a world where all people affected by health challenges live healthy lives supported by a community that cares.

#### Mission

Human Health Project's (HHP) mission is to promote peer-to-peer holistic health with three pillars: Information, Education and Support, whereby people around the world can help each other with their health issues, reducing inequities in health outcomes. HHP has a special focus on the underserved and vulnerable population groups, as well as the elderly and their caregivers.



## OUR VALUES

#### Patient-Centered Healthcare

HHP supports the patient empowerment movement and e-patient initiatives. We believe medicine should be participatory, and that individuals who are equipped with the most accurate and up-to-date health information, education, and support are empowered to make informed health decisions for themselves and those in their care.

### Peer-Led Patient Advocacy

Peer-Led patient advocacy is about supporting people who are not being heard in the healthcare system, and empowering them to use their right of autonomy. Through sharing of information, experiences, and resources, advocates inspire patients to have confidence and take ownership in their care plan.

#### **Health Information Access**

We believe people have a right to accurate and unbiased information about all types of medicines including conventional, alternative and Integrative. We believe free access to health information is not a privilege, but rather a human right that should be granted to every individual regardless of geographic location, social class, or financial position.

### Local Partnerships & Volunteer Opportunities

Our mission transcends borders, and we embrace partnerships with other nonprofit organizations. We are primarily volunteer based and rely on local volunteers and partnerships to help us fulfill our mission. Through our partnerships and volunteers, we aim to improve the lives of the most underserved and vulnerable communities around the world.

### The Universal Declaration of Human Rights

Human Health Project recognizes The Universal Declaration of Human Rights by the United Nations. Click below to read more.

Read More Here



## A PERSONAL MESSAGE FROM HHP FOUNDER AND CEO

### PHIL HARRINGTON



We now have four programs up and running, helping people help each other with their health, Real World Data, Peer-led Patient Advocacy, the Learning Academy and Peer to Peer Panels. This has been achieved primarily through the amazing work of HHP's team of dedicated volunteers along in combination with a relatively very low cash budget. Our challenge and opportunity now is to significantly increase the number of people we are reaching with our programs and in turn to also increase our funding support in order to be able to do so.

Today HHP is made up of affiliated but separate legal entities in the United States, Northern Ireland and the Republic of Ireland. At the heart of HHP's vision is the belief that individuals have a unique insight about themselves and their conditions and have a desire and willingness to share this knowledge to help and support others. Peer-to-peer support provides the opportunity for patients to learn about their conditions as well as the motivation to maintain their own health and well-being. HHP programs are led by communities, patients and volunteers who are included in every stage, from systems and product developments through to good governance at committee and trustee levels.

We are very grateful for the ongoing support from our longstanding funders, the Cole-Crone Family Foundation and ChildLife Essentials and to each and every one of our donors and volunteers for their generosity and dedication in the fulfillment of our mission.

## **IMPACT**

1. To date, over 1.3 million people from over 230 countries have visited the HHP website and received significant information on their health issues.



2. HHP's Migraine Survey has had over 13,000 respondents, and this real-world data is available to the public to help people improve their knowledge of migraine, including almost 60 different treatment options.

### 3. Migraine Data Outcomes

a) After viewing the migraine survey data, respondents who reported their understanding of migraine headaches as excellent, very good, or good increased by almost 20%.

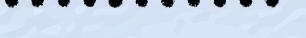


b) An increase of over 23% was observed in respondents who reported their understanding of migraine treatments as excellent, very good, or good.

c) Respondents who reported their understanding of migraine causes and triggers as excellent, very good, or good increased by 14%.



d) Over 80% of Migraine survey respondents reported the data was easy to navigate and well organized.



e) More than 70% reported that they would recommend the data to friends or family who are experiencing migraines. More than half of survey respondents said they would use the migraine data to help themselves or someone they care for.



## IMPACT

4. Provided peer advocacy training to ten volunteers through a new partnership program launched in 2020.

5. "Understanding the Healthcare System in Northern Ireland" zoom workshop.



### COVID-19 Challenges

While Covid 19 presented a barrier for the roll out of the volunteer-based aspect of the project, HHPNI quickly pivoted to the on-line delivery of the "Understanding the Healthcare System in Northern Ireland" zoom workshop. 83 people registered for the Understanding the Healthcare System in Northern Ireland workshop with 32 people attending through Zoom. Four email newsletters were sent to all registrants which included the workshop presentation, a link to a video of the presentation and a survey to track progression in key outcome areas.

#### **Workshop Outcomes**

### Ability to Navigate the Healthcare System



45% (n=19) of those who responded to the pre, and post workshop survey felt that their ability to navigate the healthcare system was much better with 43% (n=18) indicating that it was somewhat better 12% (n=5) felt that their ability to do so remained the same. Therefore 88% now have increased capacity to navigate the healthcare system which can provide critical access points for information and resources to improve their well being.

## **IMPACT**



### Taking Ownership of Healthcare

48% (n=20) felt that their ability to take ownership of their healthcare was much better with 28% (n=12) indicating that it was somewhat better 24% (n=10) felt that their ability to do so remained the same. This attitudinal change can be instrumental in people becoming an expert in their own health and standing up for themselves when they feel that health services are not responding in the way in which they should. A patient empowered with knowledge has determination and courage to speak up for themselves and participate in their plan of care.

### Ability to find credible information and/or data

Health and Social Care Trusts, Patient and Client Council, the Ombudsman, and The Regulation and Quality Improvement Authority (RQIA) are the main contact points for information and data relating to Health and Personal Social Services in Northern Ireland. However, knowing who to contact for the information needed can be challenging. 33% (n=4) felt that their ability to find credible information and/or data was much better with 42% (n=5) indicating that it was somewhat better 25% (n=2) felt that their ability to do so remained the same. Sourcing credible information and being confident in its interpretation is an important element for people in taking ownership of their healthcare.

### **Knowledge of Rights**

The Charter for Patients and Clients (1992) outlines the rights that any person using the Northern Ireland Health and Personal Services have. 59% (n=17) of those who attended the zoom workshop or accessed the accompanying materials felt that knowledge of their rights as a patient was much better with 31% (n=9) indicating that it was somewhat better, 7% (n=2) felt that their knowledge remained the same.







## HHP STRATEGY

- Deliver integrated, personalized and localized delivery of all our programs, to give people the maximum benefit from them
- Deliver our programs to people directly online and in partnership with non profit healthcare organizations
- Deliver our programs via mobile and online with maximum use of off-the-shelf applications and minimum coding
- Fund the delivery of programs and services through a sustainable combination of fee for service, grants and donations
- Grow a core paid team to complement HHP volunteers and consultants

### A. Education - The Learning Academy

HHP's Learning Academy courses are typically around 10 minutes in length and include the following elements:

- Video based course
- Text based course
- Key Takeaways PDF
- Ouiz
- Outcomes Survey
- Certificate of Completion

In Q1 2022, we released on the web, our first publicly available online Patient Education, three module course entitled Patient Driven Data and Diagnosis, the New Trailblazers in Health Research available free of charge.



Following feedback, we are now working on releasing each module as its own individual (10 minutes) course on the web and via mobile apps (IOS and Android), as follows:

- Finding Credible Information Online: Who to Trust in an Age of Misinformation
- What's Wrong with Me? What to do When You Can't get a Diagnosis
- How Real-World Data Is Transforming Healthcare

Additionally, we will launch three new single module courses in Q3 2022 which include

- Patient Empowerment and the 'epatient' Movement
- Health Literacy: What it is and Why it's Essential
- Understanding Your Patient Rights



We currently have another four courses in productions as follows:

- Building your Healthcare Team
- A Guide to Accessing Medical Records
- Managing and Protecting Opioids and Other Controlled Substances in Your Care
- Preventing Medical Errors: How to Protect Yourself and Your Loved Ones

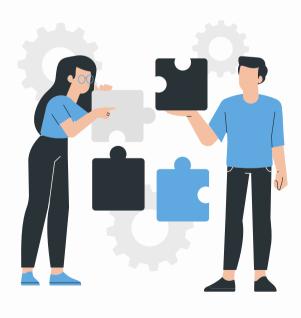
In Q1, we conducted test social media advertising, our video and graphic posts received significant numbers of social media ad views. We have reviewed and are now expanding our marketing strategy to include:

- a) Social Media advertising,
- b) Influencer marketing including bloggers
- c) YouTube marketing
- d) Partnerships including potentially Coursera and other similar websites
- e) Submission to online and offline publications.



Following a focus group on the "Understanding the Healthcare System in Northern Ireland Workshops" program, we have decided going forward to make all courses accessible to a 9 years of age and up reading level.

We are now working to be able to create and release localized audience versions of our courses in partnership with healthcare organizations in the US, India, Uganda, Ethiopia, Lesotho and going forward in other countries.



Connect with us:









#### B. Information - Real World Data

We launched a pilot of our Real World Data Program in 2016 and 2017 with the conditions Migraine and Lupus. Since then, over 13,000 people have shared data on Causes/Triggers, Symptoms and Treatments which can be viewed on 100 pages for both Migraine and Lupus. Outcomes data collected in 2019 showed that people found the data very helpful. Out of what we have learnt, we are now building the technical infrastructure to be able to allow the HHP community to share information about their health conditions in a mobile app based user friendly form boosted with artificial intelligence.

Our goal is to launch 2 new health conditions in 2022 and 4+ in 2023. Long term, over the next ten years, we plan to launch all the main 600+ health conditions. We currently have a total of 15 people working on the Real World Data team, which includes, health condition researchers, data analysts and tech team members.

In Q1 2022, we appointed Lorenzo Fritzsch in the role of RWD Tech lead (already mobile lead). We are working to be able to launch a first version of Real World Data on our mobile apps in 2023.

#### C. Online Peer to Peer Panels

In October 2020, under the leadership of Taryn May, our online Events program lead, we launched our Online Peer to Peer Panels program which has been very well received. Videos of past events can be viewed on the HHP Previous Panels page.



HUMANHEALTHPROJECT.ORG

### D. Support - Peer Led Patient Advocacy

In partnership with HHP Northern Ireland (HHPNI), we recently assisted on the completion of a pilot Peer-Led Patient Advocacy Workshops program titled, "<u>Understanding the Healthcare System in Northern Ireland</u>" which included a presentation with three modules from our nine module Patient Advocacy course:

- Your Rights as a Patient
- How to Stand up for Yourself and Be Heard
- Where to Get Help in Northern Ireland

Workshops included the presentation, followed by a Q&A with initial and final outcomes polls/surveys at the beginning and end of each workshop with all workshop content accessible to a nine years of age reading level. The pilot's independent final report "Section 3: Conclusions" are enclosed below and here is a link to the full text of the <u>Final Report</u>.

Out of what we have learnt from the pilot program, we are now working on further developing the Peer-Led Patient Advocacy Program "Understanding the Healthcare System in Northern Ireland" and plan to launch "Understanding the Healthcare System in California" in 2023. In the future, we plan to launch the program in other states and countries. We will always work to deliver our programs integrated with each other to achieve the best outcomes and maximum impact for our community.

(FROM PEER LED PATIENT ADVOCACY FINAL EVALUATION)

### 3.1 Meeting Need

The Peer Led Patient Advocacy Project (PLPAP) meets the need for people to become more aware of their health and well-being and become experts in their management of minor or chronic conditions. As primary health services post pandemic moves increasingly towards a triage remote based delivery, it is essential that people from all demographics use all the skills and resources at their disposal to monitor their conditions on a regular basis as part of a preventative and early intervention approach. This can help to reduce pressures on the healthcare system through unnecessary GP appointments or presentation at Accident and Emergency Departments.

While Covid 19 presented a barrier for the roll out of the volunteer-based aspect of the project, HHPNI quickly pivoted to the on-line delivery of the "Understanding the Healthcare System in Northern Ireland" zoom workshop. 83 people registered for the workshop with 32 people attending through Zoom. Four email newsletters were sent to all registrants which included the workshop presentation, a link to a video of the presentation and a survey to track progression in key outcome areas.

(FROM PEER LED PATIENT ADVOCACY FINAL EVALUATION)

### 3.2 Ability to Navigate the Healthcare System

45% (n=19) of those who responded to the pre, and post workshop survey felt that their ability to navigate the healthcare system was much better with 43% (n=18) indicating that it was somewhat better 12% (n=5) felt that their ability to do so remained the same. Therefore, 88% now have increased capacity to navigate the healthcare system which can provide critical access points for information and resources to improve their well being

### 3.3 Taking Ownership of Healthcare

48% (n=20) felt that their ability to take ownership of their healthcare was much better with 28% (n=12) indicating that it was somewhat better 24% (n=10) felt that their ability to do so remained the same. This attitudinal change can be instrumental in people becoming an expert in their own health and standing up for themselves when they feel that health services are not responding in the way in which they should. A patient empowered with knowledge has determination and courage to speak up for themselves and participate in their plan of care.

(FROM PEER LED PATIENT ADVOCACY FINAL EVALUATION)

### 3.4 Ability to find credible information and/or data

Health and Social Care Trusts, Patient and Client Council, the Ombudsman, and The Regulation and Quality Improvement Authority (RQIA) are the main contact points for information and data relating to Health and Personal Social Services in Northern Ireland. However, knowing who to contact for the information needed can be challenging. 33% (n=4) felt that their ability to find credible information and/or data was much better with 42% (n=5) indicating that it was somewhat better 25% (n=2) felt that their ability to do so remained the same. Sourcing credible information and being confident in its interpretation is an important element for people in taking ownership of their healthcare.

### 3.5 Knowledge of Rights

The Charter for Patients and Clients (1992) outlines the rights that any person using the Northern Ireland Health and Personal Services have. 59% (n=17) of those who attended the zoom workshop or accessed the accompanying materials felt that knowledge of their rights as a patient was much better with 31% (n=9) indicating that it was somewhat better, 7% (n=2) felt that their knowledge remained the same.

(FROM PEER LED PATIENT ADVOCACY FINAL EVALUATION)

#### 3.6 Value for Money

Based on our analysis of the above outcomes presenting from the Peer Led Patient Advocacy Project and the potential savings that it can deliver for Health services; we conclude that it has provided value for money to funders. However further investment is necessary for the project to realise its potential to be truly transformational for how people engage with their own healthcare needs in the future.

Learning Academy Patient Education Courses, Real World Data (people sharing information about their conditions with each other, from symptoms to treatment and On-line Peer to Peer Panels can make this a truly global movement. HHPNI should continue to be funded to make healthcare knowledge accessible with a particular focus on those who are marginalized or who are not digitally literate.



(FROM PEER LED PATIENT ADVOCACY FINAL EVALUATION)

#### The Future

Our goal is to improve the program as a result of feedback and outcomes from the pilot program and to launch it in US versions, starting with the launch of "Understanding the Healthcare System in California" workshops program in 2023. Our primary focus will be on people on Medical or uninsured and in Spanish and English versions.

Additionally, our goal in 2023 to 2025 is to produce and deliver the full 9 module patient advocacy video course as well as an online community application that will allow community members to create profiles, groups and forums as well as sign up for online workshops.



## OUR BOARD OF DIRECTORS



Liz Chroman



Johanna Harris



Sally Curley



John Kotick



Phil Harrington



Andreas Reiff

## OUR SUPPORTERS



























DocHub



### FINANCIAL RESULTS



### THANK YOU, GIVE & DONATE

The Human Health Project depends on the support of individuals and organizational partners like you to keep our mission helping people. To join the peer to peer holistic health movement or make a taxdeductible gift, please visit us today.

### DONATE

Platinum Transparency **2022** 

Candid.

Connect with us:









