

The European Patients' Forum (EPF) is looking to appoint a

“Data Saves Lives” Coordinator in March 2019

Deadline for applications: 15 February 2019

Interview date: 26 February 2019

Full time (100%), fixed term employment of one year with the option to extend

The “Data Saves Lives” Coordinator is responsible for the management of this new “Data Saves Lives” multi-stakeholder initiative, for which EPF hosts the Secretariat. S/he will work closely with the Institute for Innovation in Health Data (i~HD), our content partner. Please see attached concept note for further information.

The “Data Saves Lives” Coordinator is also responsible for communication and dissemination tasks in EPF digital health-related activities, such as the EHDEN (European Health Data and Evidence Network) and DIGITALHEALTHEUROPE projects and contributes to the development of this area of work with the relevant EPF team experts.

Background

The European Patients' Forum (EPF) was founded in 2003 to be the collective influential patient voice in European health and related policies and a driving force to advance patient empowerment and equitable patient access in Europe.

EPF currently represents 72 members, which are national coalitions of patient organisations and disease-specific patient organisations working at European level. EPF reflects the voice of an estimated 150 million patients living with various chronic diseases throughout Europe.

EPF's vision for the future is that all patients with chronic conditions in the Europe have access to high quality, patient-centred equitable health and related care.

The EPF strategic goals focus on areas such as health literacy, healthcare design and delivery, patient involvement, patient empowerment, sustainable patients' organisations and non-discrimination. More information: www.eu-patient.eu

Job description

Job title: “Data Saves Lives” Coordinator (100%)

Reports to: Senior Programme Manager

Purpose of the role

Research into chronic conditions and diseases, and their management and treatment is increasingly reliant on data generated by patients, physicians and other healthcare workers, hospitals and similar institutions, and many others.

Despite considerable advances in technologies to facilitate and support health-related research, it remains very challenging to be able to use health data, due to concerns of the public, and privacy, security and confidentiality issues.

To meet this challenge, the European Patients Forum (EPF) and allied organisations propose to develop an online portal on health data, to improve awareness and knowledge, promote the importance of data in health research to the public, and to create a trusted environment for dialogue about the use of health data.

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Key areas of responsibilities

The post holder will be responsible for:

Managing the Data Saves Lives Secretariat

- Organising meetings of the core group that is steering the initiative (scheduling, preparation, minute-taking, follow up)
- Liaising with the Advisory Group

- Coordinating the editorial board responsible for reviewing content
- Together with the Core Group, developing and implementing a marketing strategy for the web platform
- Preparing the launch of the web platform in late spring 2019, and co-ordinating the ongoing publicity of it after launch
- Organising regular 'data community' meetings
- Liaising with patient and public representative organisations across Europe, to support their use of the platform, responding to enquiries and communicating with EPF and i~HD contact points about any issues raised by them
- Supporting the launch of the "Data Saves Lives" campaign during 2019, its implementation and follow through into 2020
- With the core group, developing and implementing an evaluation strategy for the initiative
- Overseeing and monitoring the "Data Saves Lives" budget in accordance with EPF procedures

Content and platform coordination

- In collaboration with i~HD, our content and knowledge partner, coordinating and uploading content on the web-platform on an on-going basis
- In cooperation with our service provider, maintaining the web-platform, reviewing the timeliness of updates, accuracy of content uploads and periodically reviewing its overall content and impact, to advise on additional areas of content that may be needed

Project Communication Management

- Producing articles on projects updates, mainly in the field of Digital Health and Medical Research
- Promoting projects visibility on social media

Financial Management

- Managing the project communications budget and ensuring timely reporting

General Tasks

- Contributing to ensure a coherent communications strategy and messages with EPF
- Administrative tasks (tenders and administrative procedures in line with EPF policies)

Profile specification

Qualifications and Experience

- Bachelor's degree (or equivalent) in Health or Life Sciences, or another related/relevant field;
- 5 -years' experience in the management of projects and programmes;
- Proven experience working on multi-stakeholder projects (NGOs, industry, academia, etc.);
- Previous work experience in science communication, especially in relation to public health, and health data is highly desirable;

Knowledge, skills, abilities

- Excellent project management skills;
- Demonstrated ability to work effectively in multi-stakeholder teams, delivering through and with others;
- **Demonstrable interest and competence in data, science and technology**
- Ability to apply judgment in the context of assignments given, plan own work and manage conflicting priorities;
- Excellent interpersonal, communication, and problem-solving skills;
- Strong computer skills, including word processing, spreadsheets, presentation packages, internet, and excellent ability to navigate the social media environment;
- Proven ability with using web content management products to manage the content of one or more web sites;
- Excellent verbal and written skills in English are essential, plus working knowledge of at least another EU language is required;
- Demonstrable commitment to the vision and mission of EPF, especially in relation to promoting the meaningful involvement of patients, and the Data Saves Lives Initiative.

Desirable

- Ability to coordinate and edit reports
- Ability to design projects communications strategies and activities for projects and new project proposals
- Ability to coordinate and /or produce projects' periodic newsletters and communication tools (PPTs, videos, factsheets etc) targeting identified relevant audience

Dimensions

Staff:

EPF Team: 17
Direct reports: none

Key interfaces

Internal: EPF Staff

- Secretary General / Advisor/ Executive Director
- Senior Programme Manager

- Finance Manager
- Office Coordinator
- Policy Officer
- Communication Team

External: Please see attached concept note for further information

- “Data Saves Lives” core group
- Editorial Group
- Advisory Group
- Wider health data community

Terms

Term of appointment: Fixed term employment of one year with the option to extend

Starting date: March 2019

Location of post: EPF office, Brussels

We offer

A monthly gross salary of between 2788 and 3115 euros / month depending on experience, coupled with various benefits (lunch vouchers (8 euros/day), transportation costs within Brussels region, health care (hospitalisation and ambulatory care) and pension insurance.

To apply

Please send a cover letter and CV to recruitment2019@eu-patient.eu by 15 February 2019.

Please note that only shortlisted candidates will be contacted.

All qualified applicants will receive consideration for employment without regard to race, colour, religion, gender, gender identity or expression, sexual orientation, national origin, genetics, disability, or age.

EPF will process the data submitted by candidates for the purposes of recruitment and selection, according to its Privacy Policy: <http://www.eu-patient.eu/About-EPF/epf-privacy-policy/>. We will treat your data with the utmost care and take all appropriate steps to protect it.

DATA SAVES LIVES INITIATIVE

APPROVED CONCEPT NOTE

1. Context for this document

Stakeholder meetings in April and June confirmed support for the setup of a European Health Data Platform to raise awareness and provide information about the use of health data in order to establish trust and improve acceptance. Subsequent discussions have confirmed that industry taking the lead in funding the initiative at the start is a pragmatic way forward, but it is essential that a more balanced public-private funding model be established in the medium-term (i.e.: within 2-3 years). As a result, the structure proposed here is intended to guide the Platform through its launch phase of perhaps 18 months – 2 years, after which further adaptation to governance and other elements of this paper will be needed.

As previously discussed with stakeholders, it is intended that the Platform should generate materials which support the members' shared objectives, but that there should also be a strong element of profiling best practice by others and engaging in collaboration with like-minded organisations. Above all, we aim for engagement at member state level and it is also our ambition to reach a wider public with a Europe-wide communications campaign as the project evolves.

It is proposed that EFPIA would be the main source of funding for the Platform over the first 2 years of its operation. EFPIA will seek funding for:

- Staffing of the secretariat
- Preparatory work on strategy development and governance
- Content creation
- Social media strategy
- Meetings and conferences

2. Vision, Purpose, Objectives & Deliverables

VISION

Our vision is a Europe where informed data sharing supports health and scientific research to meet the needs of patients and address the challenges faced by our healthcare systems.

PURPOSE

Our mission is to create a European Health Data Platform that will build awareness and understanding of how data is used and provide a trusted environment for dialogue about the use of health data in Europe.

OBJECTIVES

- Promote wider public understanding and trust in how data is accessed and used responsibly and its value in supporting modern healthcare;
- Empower patients and healthcare professionals to realize the potential of new sources of data and new ways of generating them using digital technologies;
- Create resources that can be adapted for use at national/local level;
- Enable engagement with regulators, payers and other relevant stakeholders.

DELIVERABLES

- Common principles and recommendations on responsible use of health data;
- A repository of resources to empower patients and citizens to understand the data journey and engage in dialogue on the use of health data;
- A patient-led platform, engaging a wide network of stakeholders in dialogue and exchange of ideas;
- Communications campaign on the value of data sharing.

3. Governance

For this initiative to be trusted, credible and effective, it is essential to have a clear and transparent governance structure.

General principles

The Health Data Platform operates on principles of multi-stakeholder governance and is open to organisations committed to improving the understanding of health data and to engage in dialogue on health data related issues, including, but not limited to:

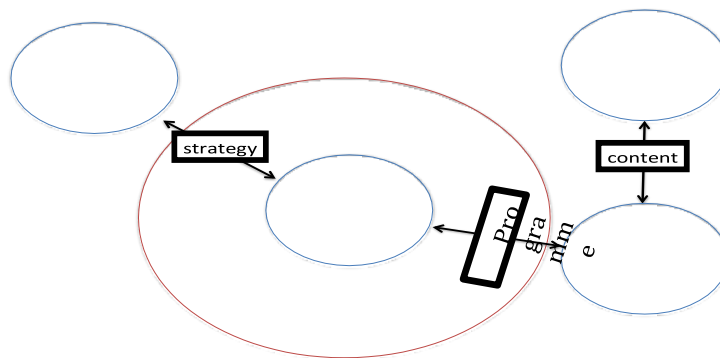
- Patient groups;
- Public Sector Researchers;
- Health Data Networks;
- Life Sciences companies.

A Core Group will be established to drive the initiative. The group will comprise of representatives of the constituencies listed above. Organisations volunteering for the Group would be asked to commit to the time needed to make the project a success. A Chair will be elected at the first meeting for a two-year period and decisions will be made by consensus. Platform “partners” not participating on the Core Group will comment on the work produced by the platform and the decisions of the Core Group.

In addition to a secretariat, we believe the credibility of the platform would be advanced by two further governance elements:

- A senior advisory group, who would comment on the overall strategy. Membership would be drawn from European Institutions, ethics experts, and senior figures from the research community;
- An editorial group that will review all resources developed by the Platform. The editorial group will be composed of five representatives including a patient representative, a health data expert, a health writer, an ethicist and an expert in plain language. The Editorial Group will be an independent body that will ensure that all material produced for the Web Platform meets the highest standards in terms of quality information.

Overall, the proposed structure looks as follows:



ANNEX: RESPONSIBILITIES

Responsibilities of the Core Group

- Ensure the Platform's has appropriate operational autonomy relative to its funding sources;
- Oversee development of the strategy;
- Agree any necessary rules governing participation in the Health Data Platform;
- Plan an annual meeting of the health data community and call additional meetings should the need arise;
- Develop a financial sustainability strategy, including transition to a public-private model;
- Agree on the need for and terms of reference of the Advisory Group and the

Editorial Group;

- Agree procedures for member consultation;
- Oversee the operational proposals of the Secretariat;
- Agree on any collaborations with third parties;

SECRETARIAT

EPF will act as the secretariat for the Platform. The secretariat's responsibilities include:

- Development of draft content and dissemination plan for approval by the Core Group;
- Propose composition of the editorial group to the Core Group for decision;
- Prepare of the Core Group meetings and Editorial Group meetings and Health Data Community meetings;
- Develop and oversee the Campaign;
- Prepare interactions with the Advisory Group;
- Oversee budget and management of expenditure;
- Oversee KPIs and project milestones;
- Propose staffing plan and make necessary recruitments;
- Oversee third party contractors' negotiations.