

Implementing Strategy into Action – First Year Results of the Office for Rare Conditions, Glasgow

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Introduction

Scotland launched a Rare Disease Implementation Plan in 2014. Awareness of this plan at the Royal Hospital for Children (RHC) Glasgow which is the largest children's hospital in Scotland is limited. For rare endocrine conditions, bone conditions and epilepsy, the hospital is an endorsed health care provider within its corresponding European Reference Network (ERN).



The Office for Rare Conditions, Glasgow

To raise awareness of rare conditions amongst health care professionals, enhance the quality of clinical care and promote participation in multi-centre research, an Office for Rare Conditions was developed in 2017 with seed corn funding from the Glasgow Children's Hospital Charity.

Achievements Of The Office For Rare Conditions

- **Steering Committee** to assist the Office in its work with health service management, clinicians, patient bodies/associations, pharmaceutical companies, patients & families.
- **Patient Advisory Group** to advise the steering committee of issues raised by parents and families who attend RHC.
- **Public Profile** through social media, the hospital and community to engage with patients and professionals
- **Scottish Government Cross Party on Rare, Genetic & Undiagnosed Conditions.**
- **Scottish Medicines Consortium Working Party** looking at access to new medicines.
- **Clinical Teams** meetings to engage with clinicians; raised awareness of rare conditions.
- **Patient association** meetings to promote working together.
- **Scottish Parliament Rare Disease Day Event.**

Engagement and raising awareness:

facebook.com/ORCGlasgow



Promoting patient events and sharing what is happening in rare conditions with patients and families.

www.officeforrareconditions.org



Newsletters and leaflets



Twitter.com/ORCGlasgow

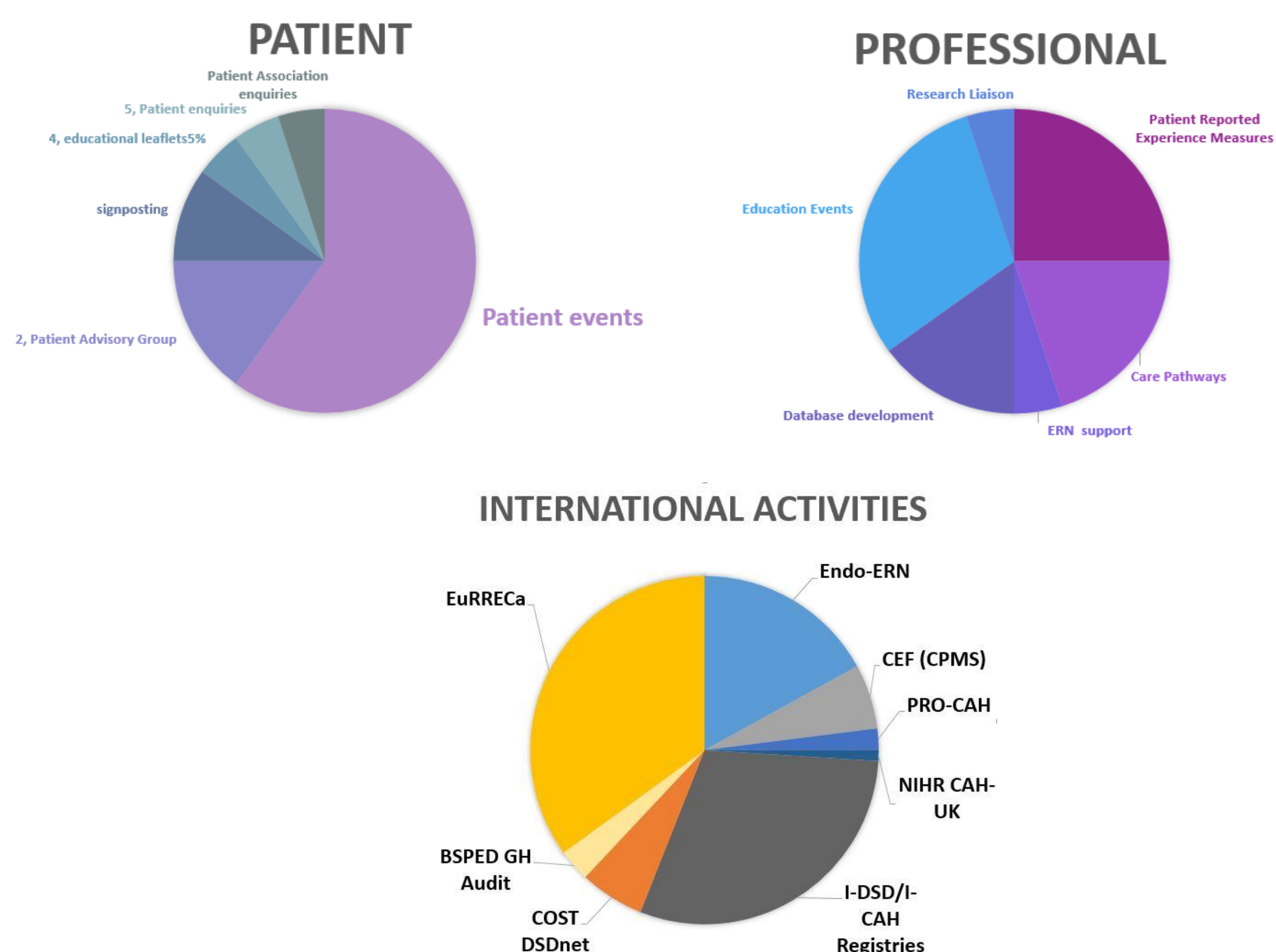


Using Twitter to reach patient organisations, health care professionals. Live tweeting rare condition events

Exhibition stands in hospital



Glasgow Facing Activity



Summary

With a small amount of funding, a “bottom up” approach based on local cooperation between patients, families and healthcare professionals has allowed the Office to listen and communicate with those working with and affected by rare conditions, highlighting good practice and working to address identified needs and gaps in services. In addition to its local activities, the Office has harnessed local research expertise that has enabled it to contribute to regional and international activities.