

The use of patient reported experiences to develop local solutions for individuals with rare and low prevalence conditions in the West of Scotland.

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Introduction

The Office for Rare Conditions aims to improve the standard of care received by people with rare conditions who attend hospitals in the West of Scotland, by developing local solutions that allow implementation of rare disease policies. The Office seeks opinion directly from patients through the Patient Reported Experience Measures (PREMS) Questionnaire.

Methods

The questionnaire was created in paper and online format and the link was posted on all of The Office's social media channels to increase awareness. It is divided into four main sections; about the condition, about the support received, about health services, and about The Office for Rare Conditions' Activities.

Results

80 questionnaires have been completed to date, 14 from patients and 66 from a parent or carer. 73 people (91%) had received a formal diagnosis, 2 (3%) were suspected to have a specific rare condition, and 5 (6%) were currently undiagnosed. Of the 73 patients who had received a diagnosis, over half (58%) had been diagnosed within 3 months of approaching health care professionals after developing symptoms. 50% of respondents said they were given little or no information around the time of diagnosis.

Information Given at Time of Diagnosis (n, 80)

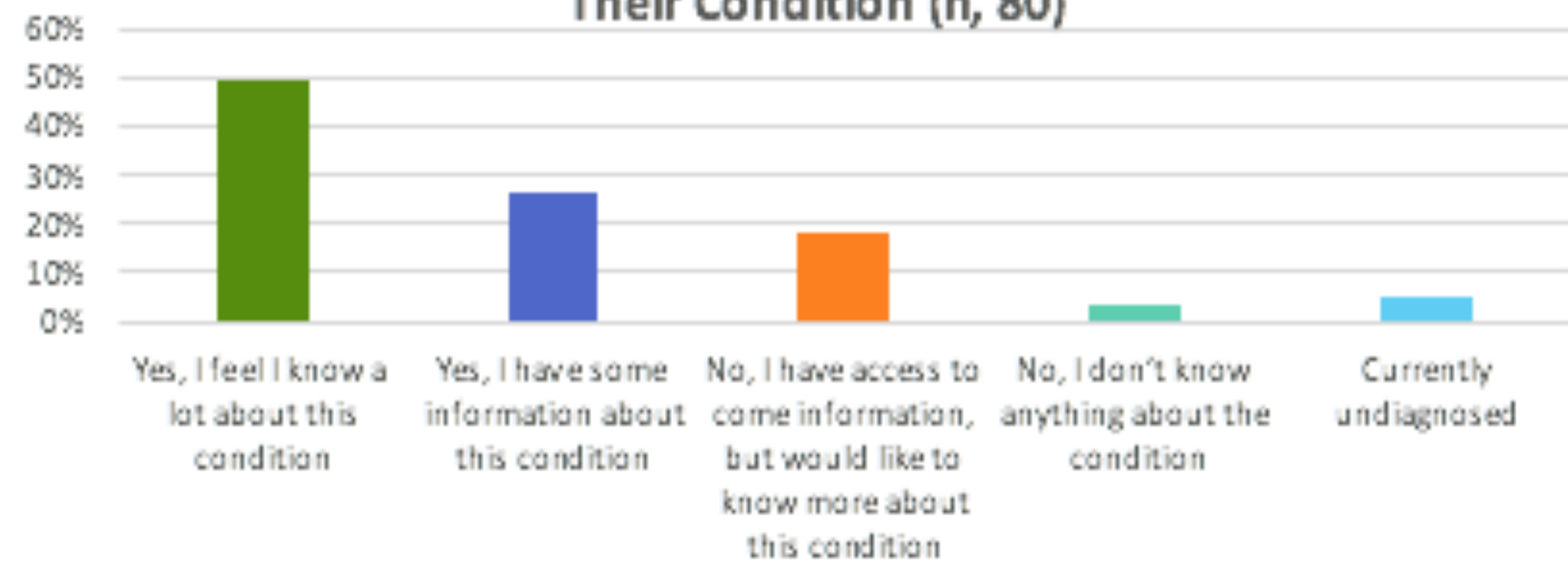


■ Lots ■ Adequate ■ Little ■ None ■ N/A [currently undiagnosed]

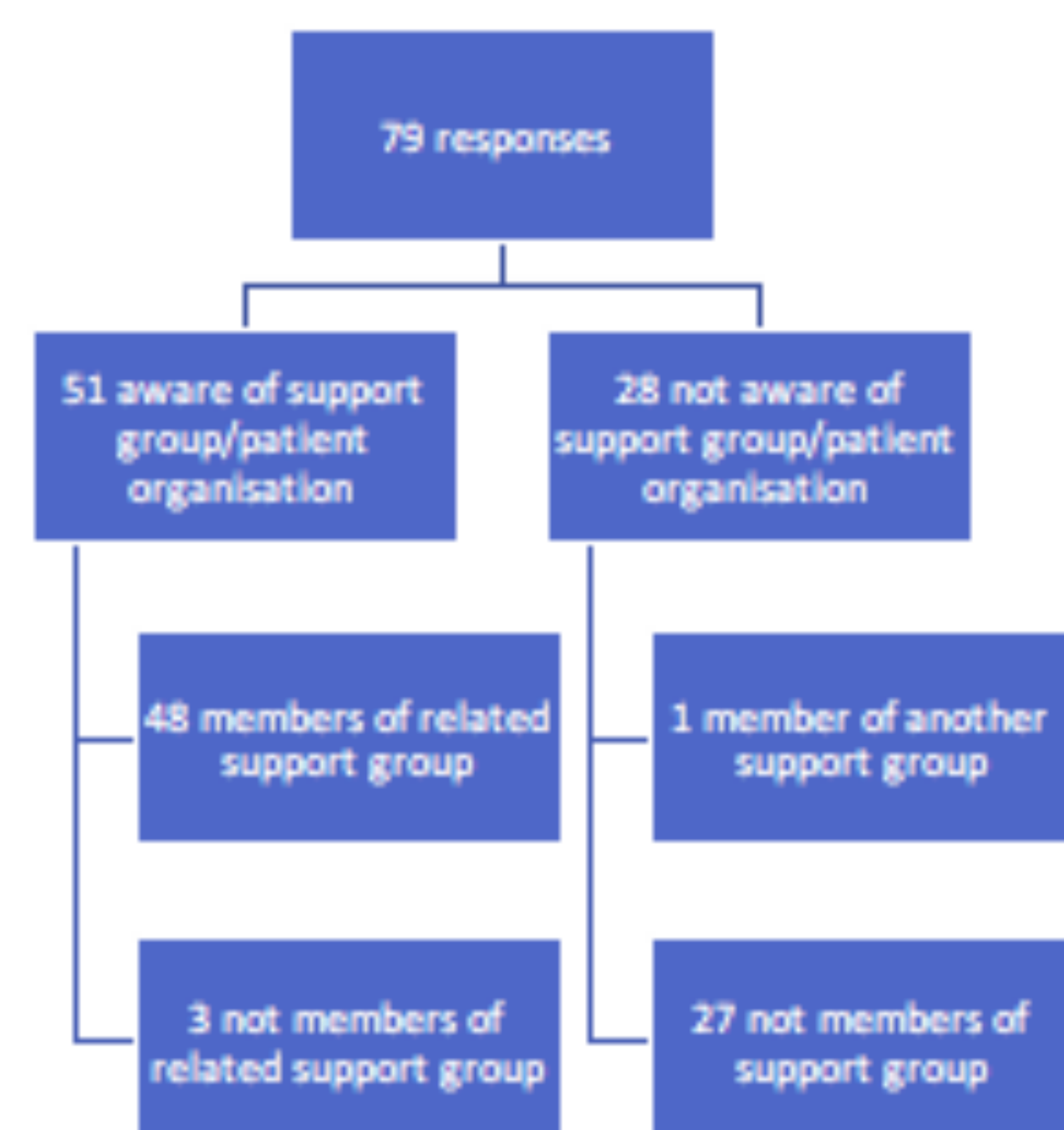
Three quarters of respondents said they had enough information on their condition, with 14 of 80 people (18%) wanting to know more and 2 people (3%) responding they knew nothing about their condition. There was a low awareness of The Office for Rare Conditions but a very positive response to interest in attending family days, with 52 (67%) of the 78 people who answered being interested.

Results continued

Do Patients Feel They Have Enough Information About Their Condition (n, 80)



Over half, 52 people of the 79 who responded to the question, said they had had the opportunity to meet another person with a similar condition, and 27 people (34%) said they had not. 66% of people were aware of a support group/patient association for their condition. Of the people aware of a support group, almost all (94%) were members. From the group of 28 people not aware of a support group/patient organisation for their condition, one individual was a member of another support group not specific to their condition.



Conclusions

In the West of Scotland there is a need to increase awareness and knowledge of rare conditions and to enhance the support that is available to children, adults and their families/carers. The PREMS questionnaire is a tool which can be used to guide the Office in their future projects.