

The benefits of collaboration as demonstrated through the development of a Starter Kit for Adults with Type 1 diabetes

K. Gilbert, R. Millard

Reality Check young adults with diabetes Inc., NSW, Australia

1,000 Australian adults are diagnosed with Type 1 diabetes each year. Information needs of this group have not been specifically investigated, and no dedicated information resources existed. Reality Check, a voluntary organisation focused on the needs of adults with Type 1 diabetes initiated a project to research and develop an educational resource, with funding from the Australian government.

There were three phases of consultation, and two phases of review. 70 people diagnosed as adults (average duration of diabetes 6.3 years, 34% male) self-reported information needs at diagnosis via email. Diabetes-specialist health care professionals' (HCPs) perception of information needs were identified through an inventory of existing resources and a survey of 33 diabetes centres. 16 telephone interviews with HCPs were conducted. Both factual and aspirational questions were asked in each phase. Results of this consultation were coded into 28 themes.

Nine themes were shared between patients and HCPs: exercise (11%,8%), pregnancy (3%,33%), others are diagnosed as adults (3%,8%), monthly hormonal changes (1%,8%), food (26%,8%), meet others same age (6%,33%), differences between types of diabetes (1%,17%), cause of Type 1 diabetes (6%,8%), and alcohol and drugs (6%,50%).

Themes with the greatest variance in rates of being identified in favour of HCPs were: counselling/mental health advice (0%,58%); legal and employment issues (0%,50%); and alcohol and drugs (6%,50%). The greatest variance in favour of patients were referral to online support (23%,0%); food (26%,8%); and stories from people with diabetes (17%,0%).

A draft resource was reviewed by 32 patients and 20 diabetes centres, 100% of which endorsed and adopted it. Within 12 months of publication, 63 diabetes centres had adopted the resource, and it had attracted sponsorship for continued production.

The project demonstrates the values of a collaborative approach to resource development with all of government, health professionals, patients and private companies contributing in different ways to fill a gap in information and resources.