



Development of a patient and clinician co-led education program to promote living well with an implantable cardioverter defibrillator: Insights from a pilot project

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ABSTRACT

Objective: To evaluate a pilot education program designed to improve patients' experience of living well with an implantable cardioverter-defibrillator (ICD).

Methods: Patient Partners with previously implanted ICD and clinicians collaboratively performed monthly education sessions for potential and recent ICD recipients. Curriculum development was informed by current evidence of ICD patients' unique educational needs; delivery format transitioned to a virtual platform following the onset of COVID-19. Participants' experience was evaluated using a tailored questionnaire to explore preliminary insights.

Results: 126 participants (median age: 62 years; women: 30%) attended 24 sessions. In-person participants (n = 62, 49.2%) reported sessions as helpful (n = 56, 94%) with regards to format and Patient Partner interactions. Virtual participants 64 (50.8%) completed an electronic survey (n = 27, 45%); reporting sufficient information for most topics with the exception of potential psychological effects of ICD implantation. Patient Partners as collaborative session leaders was perceived to be very helpful (n = 22, 82%) or somewhat helpful (n = 5, 18%).

Conclusion: This novel educational partnership met the learning needs of patients at the vulnerable time of new cardiac device implantation of both in-person and virtual formats.

Innovation: The inclusion of Patient Partners in co-led cardiac education informs novel approach to care that may improve patients' experiences of living well with complex technology.

HIGHLIGHTS

- Education sessions designed and implemented by Patient Partners and expert clinicians are feasible and well accepted.
- Patient Partners can provide support and education through sharing their lived experiences.
- In-person patient education sessions can successfully be transitioned to a virtual platform.

1. Introduction

The implantable cardioverter-defibrillator (ICD) provides effective treatment for the prevention of sudden cardiac arrest in select patients. The ICD is a permanently implanted device that recognizes potentially lethal cardiac arrhythmias and provides treatment by ventricular

anti-tachycardia pacing or a defibrillation shock of the heart to return it to a normal rhythm. In the past three decades, randomized trials have shown a relative risk reduction of up to 54% in mortality; however, the potential risks and complications of ICD implantation are associated with high prevalence of shock-related anxiety, depression and reduced quality of life (QOL) (1-3). Although patients' ability to cope and accept their device can

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be attributed to diverse factors such as mental health and multi-morbidity, the quality and amount of education provided prior to the implantation has significant implications on outcomes and QOL (4-6). Previous research has highlighted that patients with ICDs report inadequate education about potential psychological and social consequences of living with an ICD, information about deactivation at end of life and shock-related management (5,7-9). It is imperative that individuals have access to comprehensive and timely information about living with an ICD prior to implantation to help inform decision-making, improve device acceptance and reduce shock-related distress (4,10).

The development of a nurse-led educational program model that is tailored to the individual while also providing real-world experiences of having an ICD ought to include the collective expertise and perspectives of device clinicians and the program co-leadership of peers or Patient Partners (11,12). The use of Patient Partner engagement in research and health care services design have demonstrated benefits in leveraging impactful and meaningful change because of the real-world, patient perspective contributions (11,13). Based on this growing evidence, the inclusion of Patient Partners in the delivery of an ICD education session may be an effective patient-centred strategy to bring their 'voice to the table', share their lived experience, and ensure that the intervention prioritizes and is shaped by patients' perspectives and recommendations.

Conventional processes for providing ICD patient education are frequently limited to brief interactions with specialized cardiologists during the medical consultation to determine ICD candidacy and may not address individualized learning needs. We identified this significant gap in clinical practice as an opportunity for quality improvement to meet the needs of individuals' living with an ICD while leveraging the expertise and insights of Patient Partners. The purpose of this project was to design and evaluate an education program co-developed and co-led by clinicians and Patient Partners to provide education, support treatment decision and facilitate patients' adaptation to living with an ICD.

2. Methods

2.1. Conceptual framework

This quality improvement project was grounded in the Canadian Institutes of Health Research (CIHR) Knowledge to Action Framework (KTA) to guide the implementation and evaluation processes of this innovative method for providing ICD education. The CIHR KTA framework describes an iterative process that provides guidance for transforming knowledge to action using two main components consisting of (1) knowledge creation and (2) an action cycle of iterative change (14). This framework provided an established roadmap to facilitate a dynamic approach to the development, implementation and evaluation of the multiple components of our pilot clinical project informed by contemporary evidence.

2.2. Program development

2.2.1. Education session design

In 2018, our nurse-led clinical team began formulating a strategy to provide ICD education for individuals who had been referred for ICD, were considering ICD implantation, or already received an ICD. An initial project proposal was created by the Heart Rhythm Clinical Nurse Specialist (CNS). The CNS is an advanced practice nurse with specialized competencies to promote evidence-based systems transformation and optimize patient outcomes (15). The intent of the session was to provide educational content in an informal, and interactive environment whereby patients and families could receive information from clinical experts and peers living with an ICD to help them make an informed decision and be equipped to live well with an ICD. A proposal was disseminated to the multidisciplinary Heart Rhythm team to gauge interest and obtain support which was subsequently received. An invitation flyer was created to include a brief description of the session, contact information for the Heart Rhythm CNS, session date, time and locations. A consensus was reached among the team to provide

1-hour sessions on a monthly basis based on work-load and availability of the clinical leads teaching the session. Potential participants from two tertiary Vancouver sites were invited to attend the monthly sessions. Individuals were recruited through multiple communication networks, including patients' cardiologist, ICD Clinic staff, Heart Function Clinic staff, or invitation flyers located in the cardiology in-patient and out-patient areas. Family members and individuals who provided social support were welcomed and encouraged to attend. Prior to confirming registration, potential participants contacted the Heart Rhythm Program CNS to ensure appropriateness of attendance. When the sessions transitioned to a virtual platform at the onset of the COVID-19 pandemic, pre-registration was required through an email in order to receive the confidential connection details.

2.2.2. Education session curriculum

The curriculum development was informed by contemporary evidence about gaps in knowledge and patient information needs (4,9,17). Content included (1) general overview of the ICD components and function, (2) implantation procedure, (3) shock-related information, (4) living with an ICD and (5) end of life options. Each session was anchored with content delivery formatted in a PowerPoint slide deck, scheduled for 30–45 minutes, and designed to illicit a highly interactive session with questions and informal discussions among all participants. The session was facilitated by the CNS and content was presented jointly by a Cardiac Physiologist, an ICD Clinic Registered Nurse and a Patient Partner with an existing ICD. In addition, we distributed and discussed paper education materials and vetted web-based resources.

2.2.3. Patient partner engagement and recruitment

An essential component of this program development was the recruitment, training, and on-going participation of expert patient-co-leaders. We engaged the British Columbia Patient Voices Network (PVN) to recruit Patient Partners (16). The PVN matches patient volunteers with healthcare providers seeking to engage patients and families in quality care processes. The recruitment process included an intake interview followed by an orientation session with a member of the PVN to clarify expectations and responsibilities, and provide support to optimize their effective participation.

2.3. Evaluation

A key component within a KTA process is evaluation of the project. Participants who attended the session in-person completed an evaluation form consisting of two open-ended questions about their overall satisfaction and recommendations for future sessions, and an investigator-initiated pilot questionnaire to measure their satisfaction with location, scheduling and curriculum content (Appendix A). Participants attending the virtual session received an electronic survey which was revised to include questions using a Likert response scale to measure ICD session knowledge and education gaps (4,17) (Appendix B). Additionally, the team of clinicians and Patient Partners conducted informal debriefs through email or in-person following each session to evaluate and discuss the positive aspects of the session, and identify areas for improvement or other changes.

3. Results

3.1. Session attendance

The education sessions were provided monthly. Each session was consistently facilitated by the CNS, and co-led by at least one Patient Partner, the ICD Clinic nurse or Cardiac Physiologist. Between 2019 and 2021, the program was offered to 126 participants (24 sessions) with a median age of 62 years (range 26–83) with 30 % female; 62 (49.2%) participants attended the session in-person while the remaining 64 (50.8%) participated using a virtual platform. The majority of referrals were received from the participants' Electrophysiologist (34%), with 26% from the Nurse Triage Coordinator, 18 % from the ICD Clinic staff, 17 % from other specialty cardiac clinics and the remaining 5% from other sources such as advertisement flyers in the ICD recovery unit or word-of-mouth. Over time, the pattern of

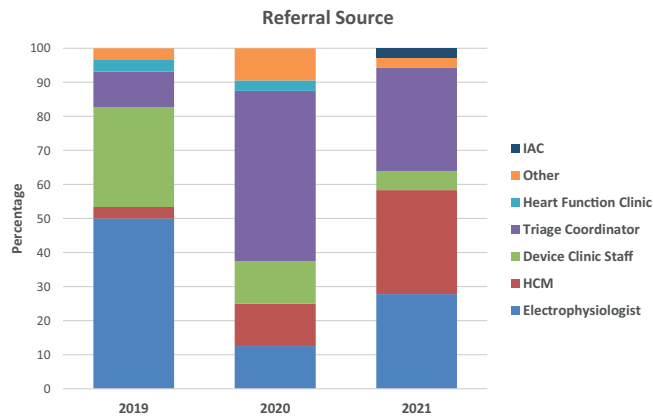


Fig. 1. Temporal change in source of referral for education session by clinician/clinic and year (2019–2021) (N = 126). *HCM = Hypertrophic Cardiomyopathy Clinic, IAC = Inherited Arrhythmia Clinic.

referrals changed from the Electrophysiologists to more diverse sources, including other cardiac specialty clinics such as the Hypertrophic Cardiomyopathy Clinic (HCM). During the 2021 calendar year, 30.5% of the referrals were received from the HCM Clinic compared to only 3% in the first year (See Fig. 1).

3.2. Session design and curriculum

We received 60 responses to the quality improvement evaluation from the 62 participants (97%) who participated in the formative in-person sessions. The logistics of in-person sessions underwent various iterations such as time of day and location based on the participant evaluation forms. Feedback indicated that day-time sessions were preferred due to family/personal commitments, parking and challenging access to hospital meeting rooms in the evening. The most significant adjustment to the session design was the rapid transition from in-person delivery at a site meeting room to the exclusive use of a virtual platform to comply with public health directives at the onset of the COVID-19 pandemic. In spite of the multiple challenges at that time, we successfully pivoted to this virtual approach and maintained the continuity of our sessions. Almost all participants who attended in-person reported finding the session helpful (n = 56, 94%) with the remaining being undecided or did not provide a response. In response to the open-ended questions regarding satisfaction and recommendations for improvement, participants consistently provided positive responses regarding the ability to see samples of ICD battery and lead equipment and to ask questions in a friendly, informal environment. The most frequent comment was the high value placed on the opportunity to

Table 1
Content evaluation of virtual session curriculum (N = 27).

Curriculum Item (Did you receive enough information about)	Definitely yes	Probably yes	Might or might not	Probably not	Definitely not
General ICD Information					
• Reasons for needing an ICD	15 (56%)	12 (44%)	0 (0%)	0 (0%)	0 (0%)
• Understand parts of an ICD	19 (70%)	7 (26%)	1 (4%)	0 (0%)	0 (0%)
• The overall function	16 (59%)	11 (41%)	0 (0%)	0 (0%)	0 (0%)
• Device and battery replacement	18 (67%)	9 (33%)	0 (0%)	0 (0%)	0 (0%)
Information about implant procedure					
• A description of the procedure	16 (59%)	11 (41%)	0 (0%)	0 (0%)	0 (0%)
• Instructions for immediate follow-up	17 (63%)	9 (33%)	1 (4%)	0 (0%)	0 (0%)
• Associated risks	16 (59%)	10 (37%)	0 (0%)	1 (4%)	0 (0%)
• Shock-related information	8 (29%)	18 (67%)	0 (0%)	1 (4%)	0 (0%)
Living with an ICD					
• Driving restrictions	16 (59%)	11 (41%)	0 (0%)	0 (0%)	0 (0%)
• Remote monitoring	11 (40%)	15 (56%)	1 (4%)	0 (0%)	0 (0%)
• Air travel	18 (67%)	7 (26%)	2 (7%)	0 (0%)	0 (0%)
• Potential psychological effects	9 (34%)	11 (40%)	5 (19%)	2 (7%)	0 (0%)
• Electromagnetic interference	13 (48%)	13 (48%)	1 (4%)	0 (0%)	0 (0%)
• Deactivation and end of life	15 (55%)	10 (37%)	1 (4%)	0 (0%)	1 (4%)

speak to their peers about their experiences living with an ICD. We received numerous requests on the evaluation form and verbally from participants at the beginning of each session for information about the experience and response to the delivery of electric shocks, and the associated anxiety. We responded by moving this content to the earliest part of our discussion to alleviate concerns and enabled a rich discussion on this topic of vital importance to ICD patients. An outline of the curriculum used to guide the education sessions can be found in Appendix C.

We subsequently surveyed a group of 60 participants who attended a virtual session, and received 27 completed questionnaires (45%). Participants reported that they generally received enough information for all the curriculum content except potential psychological aspects in which 19% (n = 5) were unsure and 7% (n = 2) report they probably did not receive enough information. A summary of the feedback for curriculum content following the virtual sessions are summarized in Table 1. Attendees also highlighted that the inclusion of Patient Partners as co-leaders of the sessions were either very helpful (n = 22, 82%) or somewhat helpful (n = 5, 18%). Additionally, all participants agreed they were comfortable using the virtual platform.

3.3. Patient partner engagement

The ICD Clinic augmented the PVN recruitment of our Patient Partners by contacting potential co-leaders to overcome the challenges of identifying individuals with lived experiences of an ICD in the general patient population. Within 12 months of beginning our program, membership of our Patient Partner group included five co-leads with diverse representation, especially related to age, sex and ICD experience. All Patient Partners have remained active participants in the education program except for one individual who experienced challenges with the technology required to use the virtual platform. The CNS endeavored to match the monthly selection of the patient co-lead(s) based on the profile of the session's participants. For example, we emphasized the importance of reflecting the age and sex demographics so that participants could easily identify with their peers. In addition, we modified the program delivery to forefront the content delivered by patient co-leads and included individual stories and perspectives in the curriculum. The program evolved from a clinician-delivered format to a Patient Partner and clinician co-led structure in light of the positive feedback and strong interest of participants in the lived experience and the expertise of their peers.

4. Discussion and conclusion

4.1. Discussion

4.1.1. Delivery of care: iterative model development

In this pilot project, we designed, implemented and conducted a pilot evaluation of an ICD information program providing key education

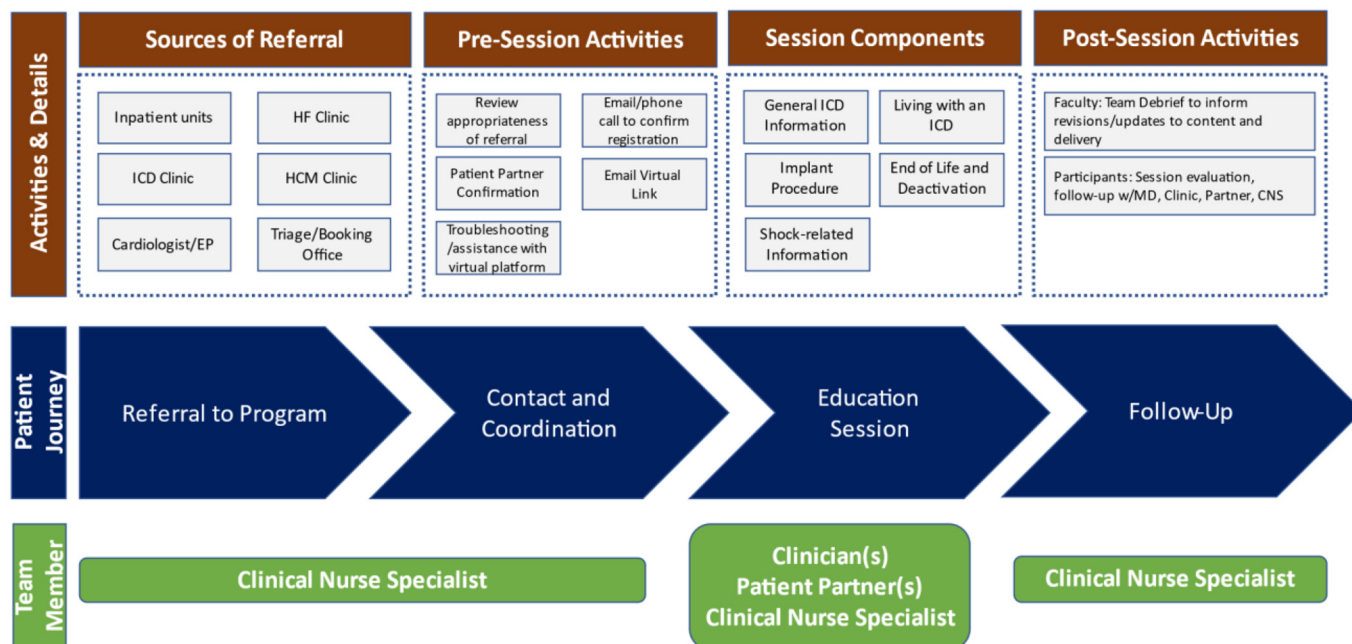


Fig. 2. Model of delivery for the ICD education program.

components to help ICD recipients receive comprehensive education through a care delivery model co-led by clinicians with device expertise and Patient Partners with previously implanted ICDs. To the best of our knowledge, this is the first report of this co-developed and co-led program in which Patient Partners play such an essential role in the delivery of ICD care. The care delivery model (Fig. 2) was developed through an iterative process of reviewing participant evaluations, ongoing assessment of the logistical needs to schedule, organize and maintain the sessions, and close collaboration among the clinician team members and Patient Partners. The specific patient and education program needs were identified to include four key components to support the patients' journey of care: (1) referral to program, (2) contact and coordination, (3) education session and (4) follow-up. Fig. 2 illustrates the program activities & details required to support the patient journey along with the team member(s) responsibilities. Educational content is provided to participants by the expert clinicians and Patient Partners however, all pre-session and post-session activities are currently performed by the Heart Rhythm CNS.

The role of the Heart Rhythm CNS was integral to the entire process of managing a comprehensive approach, beginning with the task of receiving all referrals and reviewing the clinical appropriateness of each potential participant, coordinating communication with participants and their family/social support, and leading a continuous process to review the content to inform changes and improvements to future sessions. There is paucity in the literature related to CNS-led educational initiatives; however, the contributions of CNSs to the care of patients with chronic disease and palliative care needs have shown to improve patient outcomes, reduce healthcare costs and provide positive impacts on patients and families (18-20). Additionally, an integrated review of the CNS role in cancer care reported a positive impact in provision of education, access to information and service delivery (21). As the education program continues to grow and participant registration increases, additional resources may be required to support the CNS in the pre and post education session activities.

4.1.2. Expanding access to ICD education

Sessions were initially designed to focus on pre-implantation patients with referrals generated from the Electrophysiologist during patient consultations. Interest grew rapidly as evidenced by the accelerated change in sources of referral. Our session expanded access to ICD education for patients who had undergone urgent or emergent implantation, were managed

in other specialized cardiac clinics, or simply required reinforcement and additional information. The need to identify specific learning gaps and improve access to comprehensive education in a timely way has consistently been described in recent ICD literature (5,9,25,26). Referrals to our session increasingly come from a wide variety of care-providers and clinics, creating access to education in the pre- and post-implantation period to match patients' varied journeys of care and individualized learning needs. Moreover, the ICD session provided opportunity to connect with specialty cardiac clinics such as the HCM Clinic, which may operate outside of conventional Heart Rhythm programs but includes a patient population in which treatment with an ICD exists. The growing network of referral sources across various care delivery touchpoints of our Heart Rhythm Program has been instrumental to our successful outreach, and reflects the need for the delivery of specialized education and support services in close partnership with in-patient units, specialty cardiac clinics and other care providers.

Pandemic restrictions for health care services world-wide prompted many providers to re-think ways to continue providing clinical care and effective patient education. Our project demonstrated the feasibility and patient satisfaction associated with pivoting our education session to a virtual delivery platform. Rosman et al. (27) reported beneficial effects to guideline-recommended self-care and overall well-being in patients with atrial fibrillation (AF) in a pilot study investigating a virtual AF self-management program. Additionally, utilizing a virtual platform for education delivery offers convenience and opportunity for participants who are restricted by geographical location, work obligations or financial resources to attend in-person sessions (27,28). This is supported by our findings which allowed participants living in rural areas access to ICD education which otherwise may have been challenging due to the inconvenience and costs associated with travel. Utilizing a virtual platform also facilitated opportunity for participants' family and caregivers to participate which is an integral component to achieving wellbeing and improved QOL for many individuals (5,9). Compared to in-person teaching, recognizing visual cues and facilitating informal discussion was more difficult and, similar to other virtual education sessions, challenges were encountered with some participants requiring additional technical support using the virtual platform (28,29). As healthcare providers, it is important to develop new strategies and creative ways to provide comprehensive education, address the varied learning needs of our patients, and promote equity of care.

4.1.3. Meeting patients' needs: evidence-based education and peer support

ICD educational material obtained online or through care providers conventionally focuses on ICD function, implant and immediate follow-up care (5,6,9). Our sessions augmented this content with a greater emphasis on topics related to lifestyle and living well with an ICD. We utilized an informal setting for group education delivery allowing information to be tailored to the individual needs of participants identified through discussion with the clinicians and Patient Partners. This approach facilitated our ability to meet learning needs and address gaps in education which have been reported in the literature (9,26,30). We recognized the most significant concerns of many participants were related to ICD shocks and potential psychological effects of implantation. Therefore, we modified the curriculum to provide more detailed information about psychology support and to address ICD shocks at the start of each session. Fear and shock-related anxiety have commonly been identified in ICD patients demonstrating that timely and sufficient shock-related education should be included in education programs prior to ICD implant (4-6,9).

The collaborative delivery model of clinicians and Patient Partners as co-leads for this education program has exceeded our expectations of participants' satisfaction of the session. The Patient Partners were integral to the success of our session validated by the participants' continued interest to ask questions and pursue further conversation with the Patient Partners after each session concludes. The evaluations supported this with feedback demonstrating Patient Partners as key providers of sharing experiences and stories of living with an ICD. When incorporating Patient Partners in health services development, key criteria ought to be considered in order to achieve success and meaningful relationships. This may include conducting a thorough and purposive recruitment and orientation process, active involvement and commitment from all partners, ensuring the facilitator has the skills to engage the clinicians and partners as co-leaders, empowering Patient Partners to share their experiences in a non-threatening environment and evaluating progress and collaborating to enact changes as team (31,32). Research supports incorporating a patient or user perspectives in design and delivery of health care services and informing health care policy to improve processes of care and patient outcomes (11,31-33). While engaging Patient Partners in research is not a new concept, (13,34) to our knowledge, there is limited reports describing Patient Partners engaging in formal patient education programs. Our approach to this program is unique by utilizing the device expertise of clinicians, and the lived experience of a Patient Partner to educate and provide peer support which can empower participants to make informed decisions and learn strategies to live well with an ICD.

4.1.4. Limitations and implications for research

The aim of this paper was to report on a pilot project and the multiple iterative changes made to achieve our objectives. The study of feasibility is an essential component to refine the intervention and address the operational barriers and facilitators (35). The findings can be leveraged for future research to determine the impact of the program, and focus on the measurement of patient-reported outcomes (PROs) and experiences (PREs) to capture patients' perspectives. For example, the measurement of a condition-specific patient reports such as the Florida Patient Acceptance Survey (FPAS) and the Florida Shock Anxiety Scale (FSAS) would provide unique insights to ascertain the effect of the group education session compared to more conventional care. This could provide valuable insight to inform strategies to address specific anxieties, assess psychological difficulties associated with device acceptance and improve education and support to the ICD population (36,37).

4.2. Innovation

Cardiac programs that provide ICD services must be attentive to the needs of the individual patient to optimize acceptance of the device and capacity to benefit from treatment. This ought to include developing innovative strategies to ensure timely and comprehensive education. Pandemic restrictions required the cardiac team to transition to a virtual delivery

platform that continued to provide an interactive learning session with expert clinicians and peer support. This innovative approach to patient education was well received by participants, convenient for Patient Partners and clinicians delivering the session, and expanded access to the program for individuals living in rural and remote areas.

Patient Partners with lived experience of ICD provide unique insights to support patients at earlier points of treatment. Patient education that combines clinical expertise, awareness and the lived experiences from Patient Partners is a novel and transformative way to provide patient-centered care. This pilot project demonstrated that heart rhythm expert clinicians are well positioned to co-lead novel educational approaches to improve patients' experiences and outcomes after ICD implantation.

4.3. Conclusion

Living well with an ICD presents many challenges. The prospect of significant lifestyle changes, and the experiences of uncertainty, anxiety and health consequences can be overwhelming to many individuals. This education program has provided a novel approach to providing comprehensive education about ICDs through a clinician and Patient Partner co-led program. It has promoted inclusion of the lived experiences of Patient Partners while ensuring that the dissemination of information remains grounded in evidence provided by health care providers with strong clinical expertise empowering individuals to inform decision-making and live well with an ICD.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2022.100104>.

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