Insulin pumps in diabetes care in Ireland

Written by Dr Katarzyna Gajewska, Lecturer, Department of Public Health and Epidemiology, RCSI

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People living with chronic conditions in Ireland have their medicines fully reimbursed through the Long-Term Illness Scheme, which significantly reduces their health-related out-of-pocket expenses. Irish people living with either type 1 or type 2 diabetes, have almost all of their medicines reimbursed, including the costs associated with modern technology used to better manage and control diabetes: insulin pump therapy (or Continuous Subcutaneous Insulin Infusion – CSII) and continuous glucose monitoring (CGM). Ireland is in the minority of countries worldwide, that offers almost full reimbursement of costs associated with chronic conditions (together with, for example, France, or the UK etc.), thus people with diabetes in Ireland may consider themselves lucky.

The reimbursement, however, does not mean that the majority of the type 1 diabetes (T1D) population uses the best available treatments. Insulin pump therapy is accepted as an effective and safe method of insulin delivery for people with T1D of all ages, and is recommended as a first-choice treatment for pre-school children. Many systematic reviews and meta-analyses suggest that the better accuracy of insulin delivery in CSII provides better treatment outcomes (blood-sugar control, reduced risk of developing diabetes-related complications), reduces the frequency of and time spent in hypoglycaemia, is cost-effective, and increases the quality of life when compared with the most popular treatment – Multiple Daily Injections (MDI). But anecdotal observation, discussions with people living with diabetes, patient advocates and health-care professionals (HCP), gave me an impression that CSII is not frequently used in Ireland. Thus, together with my supervisors: Prof. Seamus Sreenan (Clinician, Consultant Endocrinologist), Prof. Kathleen Bennett (Epidemiologist), and Dr. Regien Biesma (Public Health Specialist), we aimed to investigate the uptake and access to CSII by adults with type 1 diabetes in Ireland as part of the HRB funded SPHeRE (Structured Population and Health-services Research Education) doctoral thesis conducted in RCSI: University of Medicine and Health Sciences in 2015-2020.

Prevalence and uptake of CSII

To assess the uptake of insulin pump therapy in Ireland, we had to estimate the prevalence of T1D in Ireland first - there is no diabetes registry in Ireland and this data was unavailable. We used the Irish Health Service Executive Primary Care Reimbursement Service (HSE-PCRS) national pharmacy claims database data from the years 2011-16 and selected definition criteria based on the prescribed prescriptions. Those who met our definition criteria were assessed as prevalent cases. The methodology of this epidemiological study is better described in the original article[1].

Of 20,081 people meeting the "T1D" criteria in 2016, the majority (85%) were adults (n=17,053). Of the adult population, only 6.8% used CSII, and the uptake varied from as low as 2% (Co. Roscommon) to 9.6% in Co. Kildare and Wicklow. Irish data (6.8%) suggests under-utilization of CSII in people over 18 in Ireland (Figure 1). When comparing with other countries where the reimbursement is offered, uptake in adults has been reported to vary from 9.4% in Scotland, to 15% in England and Italy (data from 2017), 21% in Denmark (in one region),

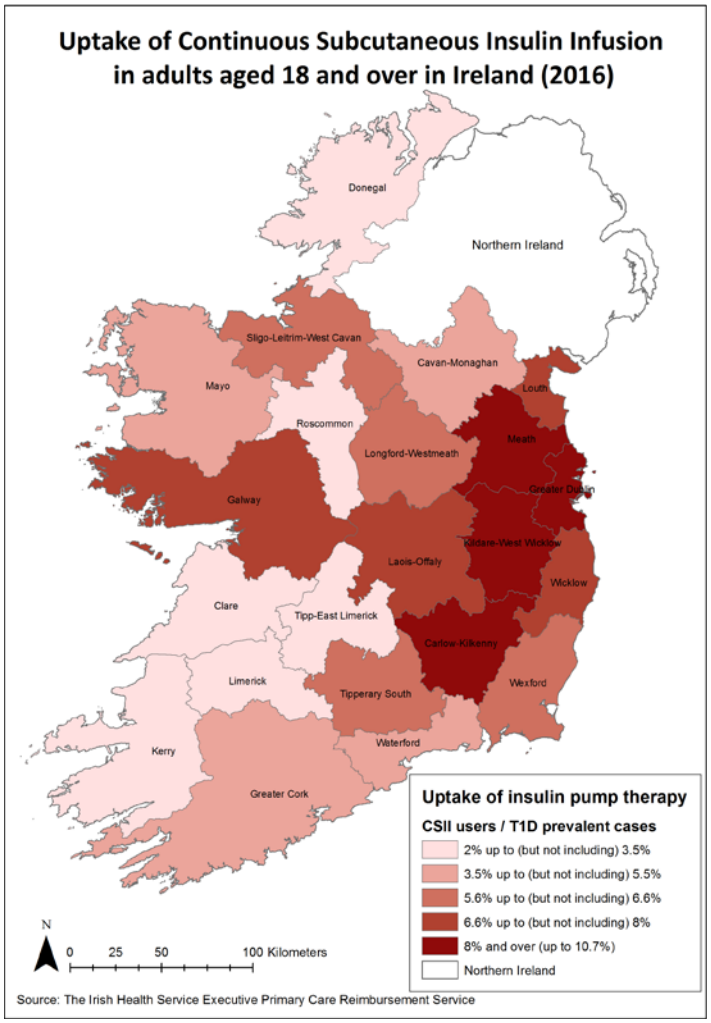
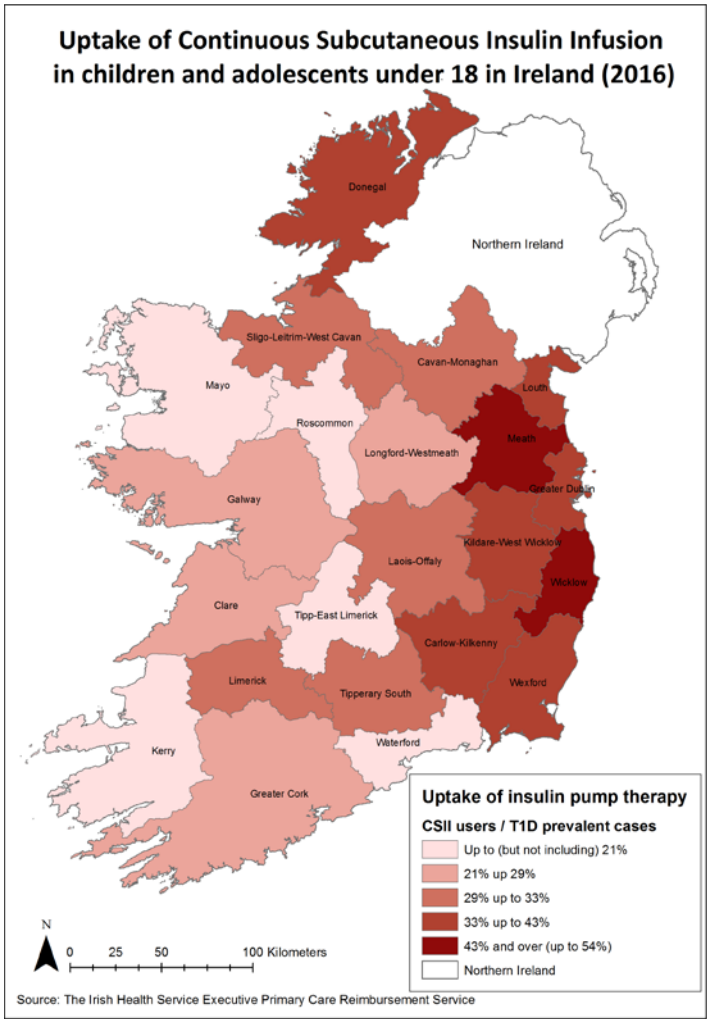


Figure 1

22% in Sweden (data from 2015), and 37% in Germany (2017). In the United States (US), the uptake of CSII is reported as high as 58% in the clinics involved in the T1D Exchange registry.[2]

Uptake of CSII is generally lower in adults than in children and adolescents, and Irish data are no different - the uptake of CSII was five-fold higher (34.7%) in the paediatric population than in adults. It also varied significantly from 12.6% in Co. Mayo to 53.7% in Co. Meath. The uptake of CSII in children and adolescents in Ireland is similar to that in the UK where it was reported as 35.7% (England and Wales, 2019 Scotland, 2017), but still lower than in other "Western" countries. The highest uptake of CSII in children and adolescents was observed in Slovenia (74%), with Sweden, Germany and Denmark also having >50% uptake. The evidence from the US T1D Exchange registry suggests an uptake of 60% in the paediatric population in 2014[2] (Figure 2).

Figure 2



Availability of CSII in diabetes clinics

The reasons behind the underutilization in adults are partly associated with poor access to insulin pump therapy across the country, and centralisation of type 1 diabetes services in Dublin. According to the survey of all Irish adult diabetes clinics conducted in 2018, one-third of Irish diabetes clinics (n=15) do not provide any type of support for patients willing to commence CSII or those who are using pumps. Based on the survey findings, access to CSII was unavailable for 11% of adults with type 1 diabetes, and uptake was usually higher in the counties where training to commence CSII was offered. However, fewer than half of the diabetes clinics in Ireland offer training to commence CSII, and even in these clinics the uptake of CSII is still low when compared to other countries' national data. Those clinics were usually based in, and around Dublin, hence, the highest uptake was observed in the East of Ireland. Except for Co. Galway, the clinics in the West of Ireland (Co. Limerick, Kerry, Greater Cork) were not offering CSII support in 2018. In Co. Galway the uptake was relatively high – mainly due to sufficient resources (i.e. the level of WTE for endocrinologists in one clinic is the highest in Ireland)[3].

Barriers to accessing pumps: "postcode lottery"

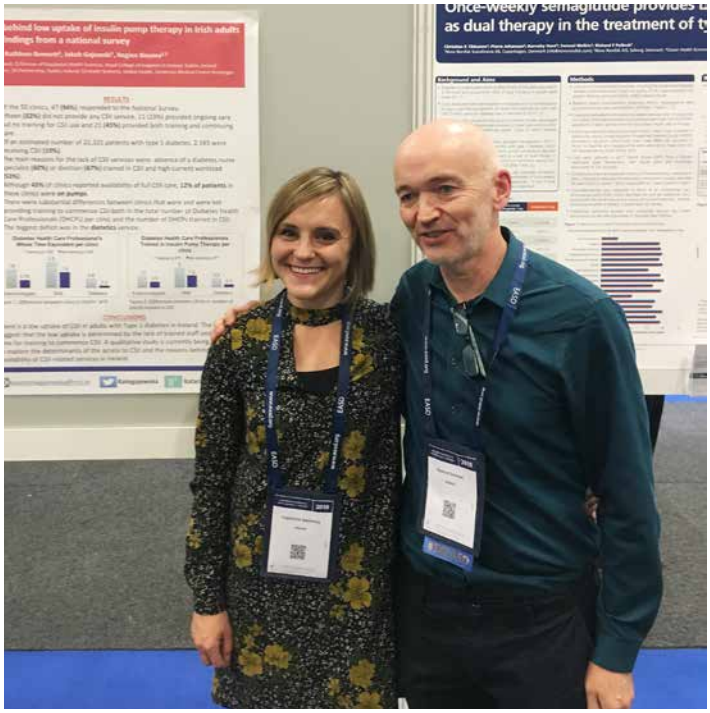
The barriers and enablers to accessing insulin pump therapy by adults were explored through semi-structured interviews with HCPs, key stakeholders, policy-makers, patient advocates and pharma reps, and through focus groups with people living with diabetes (PwD) in areas of high and low uptake of CSII. This qualitative study provided deeper insight into the determinants of the uptake in Ireland. Firstly, all discussions highlighted inequality in accessing CSII in Ireland mainly related to a place where a PwD lives. There was general agreement among participants that the uptake of CSII is low in Ireland, and that the "postcode lottery", understood as an unequal provision of services, exists. This postcode lottery ensues. ***If you live in the right place you get the best care, if you live in the wrong place you get screwed*** (Key Stakeholder 1).

This inequality was "frustrating" for all participants and it was "obvious" that low uptake is caused by the lack of local access to CSII: participants from the areas of low uptake have to travel, pay and spend their time to access care; thus, it requires significant motivation and willingness. The awareness of such solutions is also lower in areas of low uptake. If there is only one clinic in the county, and it is not offering insulin pump therapy, their choice of diabetes team or consultant is limited. They can only access CSII privately, and overall they have to put much more effort to access CSII much more than those living in areas where access to CSII is easier more available. The "Conceptual Framework of accessing diabetes-related technology" presents four main themes consisting of 18 categories. More detailed description available in Acta Diabetologica, 58, 93–105 (2021). https://doi.org/10.1007/s00592- 020-01595-5, or by e-mail request (katarzynagajewska@rcsi.com). The overarching themes were (from the least frequently discussed to the most): awareness, structure, capacity and impact of an individual.

The role of individual preferences

The main conclusion of this study is that if the structure of the health-service is insufficient (e.g., lack of standardized criteria or a referral pathway) and the quality of care and HCP expertise in this area is not standardized (CSII not always included in specialist training), and if capacity is poor (e.g., under-resourced clinics), CSII uptake appears to be impacted by individuals (HCP and patients): their interest, leadership skills, willingness and motivation. These factors may make the regional differences in accessing diabetes-related technology and the quality of care more evident. Moreover, according to the vast majority of participants, endocrinologists are "the gatekeepers" to accessing CSII. ***HCP and their attitude toward it as gatekeepers is absolutely huge if they don't see the need for pump therapy, then it is going to be very challenging for you to get your hands on a pump. So, they are a key barrier or facilitator. Some consultants are very supportive and others not so much.*** (Key stakeholder 2).

The "gatekeeping" may partially be explained by the fact that a specialist who provides diabetes care in Ireland is also (mainly!) trained in endocrinology, and



Dr Kataryzna Gajewska with Primary Supervisor Professor Seamus Sreenan at the European Association for the Study of Diabetes (EASD) meeting in Berlin 2018

a lot depends on the personal interest of the HCP. ***I am not really a diabetes guy, I am more of an endocrinology guy*** (Key Stakeholder 3). Specialists who are more interested in endocrinology than diabetes were seen as less likely to offer CSII. Lack of interest in CSII, and leadership skills were a HCP-related barrier to CSII provision: ***If a consultant has no interest in insulin pump or never trained, or an endocrinologist who has no experience in that and has no interest in developing it, it will never develop*** (Key Stakeholder 4).

"Fighting" for access

There was a consensus among all participants, that the main barrier to CSII from the PwD side was the lack of willingness to do so, or a lack of interest in diabetes. Some of them "don't want to be attached" to anything, or report that CSII does not suit their lifestyle and needs, and this preference should be respected. The lack of initiative and motivation to consider CSII might sometimes be determined by poor empowerment, diabetes stigma or even burnout, or just no strong motivation and capacity to "fight". There was agreement among all PwD in this study that they have to fight to access technology, in particular in rural areas. ***I went into XXX (consultant) and I was like: "it's as simple as this, I'm not leaving until you give me a letter to go to the YYY (clinic offering CSII)". I said "I'm done with injections" like*** (Key Stakeholder 5). Other ways of "fighting" included: "being vocal"; contacting politicians; involving media and government to "push" hospital management. All participants agreed, however, that adult PwD were generally ess effective in advocating for the use of CSII than parents of children with diabetes, who were "more concerned with getting the best available treatment for their children".

The uptake of CSII in paediatric patients might be higher in children than in adults due to better awareness of its benefits, and available policy documents (i.e. the pediatric model of care for CSII that prioritise access to insulin pump therapy for children under five). Reliable information about CSII should be provided to PwD in Ireland to enable them to make an informed decision regarding commencing CSII. Other facilitating aspects included: individual respectful cooperation between diabetes teams and patients, better access to diabetes education, standardized "criteria" to commence CSII, and awareness.

To conclude, this PhD research contributes to the scarce evidence on access to CSII (or any other complex diabetes technology) for adult people living with diabetes. Although technological advancements in diabetes are well-known and influence the quality of diabetes care and the lives of PwD, uptake is limited by lack of individual motivation and interest, health system structural issues, service capacity, awareness and PwD demand. The results of this study may inform HCP and policy-makers regarding gaps in the delivery of diabetes care, and suggest solutions to reduce the disparities in health service provision in the countries where reimbursement of diabetes technology is offered. Such steps may include the development of national guidelines, models of care, standardized HCP straining, diabetes education, and structured approaches to provide equal access to CSII across the country.

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Insulin Pumps available in Ireland