

**Clinical Nurse Specialists Diabetes Integrated Care (CNSp): A National Survey  
of Patient Experience.**

**National Diabetes Integrated Care Nurse Network Group**



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## Abbreviations

CHO	Community Health Care Organisation
CNSp	Clinical Nurse Specialist
GP	General Practitioner
HSE	Health Service Executive
MDT	Multidisciplinary Team
MOC	Model of Integrated Care for patients with Type 2 Diabetes
NALA	National Adult Literacy Agency
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
WTE	Whole Time Equivalent

## Executive Summary

### Report Aims:

1. To measure the overall patient experience as part of an evaluation of a nurse specialist-led diabetes integrated care service.
2. To build on previous reports of Clinical Nurse Specialists Diabetes Integrated Care (CNSp) activity, focusing specifically on GP visits and patient episodes of care.

### Data Source:

- Patient experience questionnaires were distributed between June and August 2018.
- 33 of the 34 CNSp (32.46 WTE) currently employed in Ireland recruited participants.
- 315 patients completed questionnaires.

### Key Findings:

- Patient consultations with the CNSp typically lasted between 30-45 minutes.
- 99% of participants felt the prior notice of their appointment was satisfactory.
- 92% of participants reported their feet were checked during the consultation.
- 98% of participants felt that the CNSp explained their condition in a clear and concise manner and received answers to questions they could understand.
- 98% of participants had enough time to discuss blood results and treatment plans with the CNSp.
- 97% of participants were involved as much as they wanted to be in decisions about their care and treatments.
- 94% of participants received enough information to manage their diabetes.
- 99% of participants rated their overall experience between good and very good.

### Recommendations:

1. Consideration should be given to how further evaluation of these CNSp posts can be supported and incorporated as part of ongoing service delivery.
2. ICT infrastructure to support electronic data capture is required to evaluate whether CNSp interventions improve patient biomedical outcomes.
3. Further research should consider the perspective of primary health care professionals who access this service, e.g. GPs and Practice Nurses.

## Background

The number of people with type 2 diabetes mellitus (T2DM) is rising in Ireland<sup>1</sup>, placing a significant financial burden on the healthcare system.<sup>2</sup> The condition also places a burden on people with diabetes and their families, the Health Service Executive (HSE), and society as a whole. Diabetes is associated with a number of co-morbidities and requires self-management and ongoing input from primary care and a variety of specialist care providers. Integrated care is seen as a way to improve the quality of patient care and better meet the complex needs of patients with long-term care conditions like diabetes.<sup>3,4</sup> The guiding principle of integrated care is to organise and co-ordinate management between and within care settings such that they receive the 'right services' in the 'right place' appropriate to their needs.<sup>5</sup>

## Integrated diabetes care in Ireland

Diabetes care in Ireland has historically been delivered in an unstructured approach with a lack of integration between primary and secondary care.<sup>6-10</sup> In some areas of the country, care is primarily hospital-based; in others, care is delivered in general practice but on an ad-hoc or opportunistic basis. Approaches to improve and integrate diabetes care include long-standing, locally driven, and more recent, nationally led reforms to reorganise diabetes care, which build on local efforts. The establishment of the National Clinical Programme for Diabetes in 2011<sup>11</sup> led to the development of a Model of Integrated Care for patients with T2DM (MOC) which outlines where patients should be cared for according to the complexity of their condition. Patients with uncomplicated T2DM are managed in primary care, patients with complicated T2DM are managed between primary and secondary care, and patients with Type 1 diabetes mellitus (T1DM) are managed in secondary care. This MOC is still in the early stages of implementation, and, as yet, is not fully embedded in the

health system.<sup>11</sup> The appointment of community-based Clinical Nurse Specialists Diabetes Integrated Care is fundamental to this new diabetes MOC.

## Clinical Nurse Specialist Diabetes Integrated Care

The diabetes clinical nurse specialist is integral to supporting chronic disease management in primary and secondary care. This role historically was based in secondary care and facilitated some integration between settings.<sup>12-14</sup> The creation of Clinical Nurse Specialist Diabetes Integrated Care (CNSp), a bespoke role operating between primary and secondary care, has greatly improved this integrative function.<sup>12</sup> In addition to delivering specialist nursing care these CNSp provide specialist support to primary and secondary care, review patients referred to them by the general practitioner (GP) or practice nurse and provide training and support to practice nurses and GPs in the set-up and delivery of integrated diabetes care.<sup>15</sup> CNSp also deliver structured patient education as well as educational programmes for health care professionals. They carry out research and audit, using audit data to influence integrated care at practice level. CNSp spend approximately 80% of their working time in primary care and 20% in secondary care which enables them to support the integration of patient care between primary and secondary care settings. CNSp facilitate and coordinate the escalation of care from primary to secondary care where indicated, engage in case discussion with the multidisciplinary team (MDT) in secondary care, support the delivery of outpatient clinics, and, where feasible, identify patients suitable for integrated management.<sup>16</sup> A report on CNSp activity in 2017 highlighted the work conducted by them over a 12-month period (Table 1).

**Table 1: Summary of activity carried out by CNSp in 2017**

- 29 CNSp representing 28.46 WTE
- 2,408 GP practice visits
- A median of 23 practice visits made per Whole Time Equivalent (WTE) per quarter
- 11,619 patient episodes, 67% (n = 7737) of which were patients with complicated type 2 diabetes
- 1,584 (14%) patient care episodes discussed with a member of the multidisciplinary team within secondary care
- 240 healthcare professional education group sessions delivered
- 226 structured patient education group sessions delivered

*Table 1: Summary of activity carried out by CNSp in 2017*

## Patient experience

Improving the quality of care is a goal of health systems worldwide. Patient experience can be used as an indicator of healthcare quality.<sup>17-19</sup> Measuring experience may identify problems in care delivery and help professionals to reflect on their own practice.<sup>20, 21</sup> Patient experience is distinct from patient satisfaction in that the former asks for information on what happened to someone when they used a service rather than whether they were satisfied with that service.<sup>22</sup> The first HSE National Patient Experience Survey was conducted in 2017.<sup>23</sup>

Models of integrated care have been found to impact favourably on patient satisfaction.<sup>24</sup> Baxter et al., identified nine UK studies of integrated care across different services, including diabetes.<sup>25</sup> These studies reported high levels of patient satisfaction.<sup>24</sup> Few studies have explored the patient perspective as part of evaluations of integrated diabetes care<sup>26</sup> or their experience of nurse specialist-led integrated care.<sup>27</sup> While some insight into the delivery of new CNSp service has been provided to date by a national survey<sup>15</sup>, an audit of CNSp activity<sup>28</sup>, and qualitative work exploring

the views of GP and practice nurses on a local CNSp service<sup>29</sup>, there has been little evaluation of the CNSp nationally. The current work aims to begin to address that gap by measuring patient experience of the CNSp service in Ireland.

## Methods

### Questionnaire

The survey was developed by CNSp in conjunction with the Evidence to Support Prevention Implementation and Translation (ESPRIT) research group at University College Cork (UCC). The questions on patient experience were modified from the National Patient Experience Survey, which originated from a library of questions developed by the Picker Institute.<sup>30</sup>

The questionnaire was piloted among 10 patients, by five CNSp, to check the clarity of wording and understanding. Each CNSp distributed questionnaires to two consecutive patients. As some participants included their own names, the questionnaire was subsequently revised to emphasise participants should not provide this information. No other revisions were made to the questionnaire as it could be completed satisfactorily by patients and they raised no issues with the content and questions. The questionnaire contained 17 closed questions and three open-ended questions about the CNSp service.

Questions included aspects of care relating to the consultation with the CNSp such as: notice given of appointment, privacy during consultation, whether foot assessment was performed, and nurse-patient communication. Patients were asked to rate their overall experience on a scale of one to ten. Three open-ended questions asked patients to comment on positive things about the consultation, things that may be improved, and finally, to provide any general overall feedback. The final open-

ended questions were designed to allow the patient to give their own feedback on the service, in their own words.

### Participants and sampling

Participants were recruited by CNSp across the nine Community Healthcare Organizations (CHO) in Ireland. Eligible participants were people with diabetes who had attended the CNSp service and who had the mental and physical capacity to complete the questionnaire. Those responsible for distributing the questionnaire at the general practice assessed eligibility.

Consecutive, eligible patients were invited to participate in this research between June and August 2018 until there were 10 participants per CNSp. Patients were invited following their consultation with a CNSp. Most questionnaires were distributed by receptionists or practice nurses with some distributed by the CNSp in general practices where this was not feasible. After completing the questionnaire, patients placed them in a sealed box. The survey was anonymous; participants did not provide their name or contact details.

### Ethics

Ethical approval to conduct the study was obtained from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. Participants were given an information sheet explaining the study and outlining what was required from them. Participants were asked to indicate consent at the beginning of the questionnaire.

## Data management and analysis

Data were cleaned in Excel before importing into IBM SPSS Version 22 for data analysis.

Descriptive statistics were used to summarize and analyse characteristics. Fisher's exact tests were used to test differences in experience by patient demographics (age and gender).<sup>31</sup> Open-ended responses were managed in Excel and analysed thematically.<sup>32, 33</sup>

## Results

### Sample population

In total, 33 CNSp of the 34 (32.46 WTE) currently employed in Ireland recruited participants. One CNSp declined to participate, having already completed a patient satisfaction survey. A variety of distribution methods were employed. Fifty two percent of CNSp, (n = 17) had receptionists distribute questionnaires, 9% (n = 3) had practice nurses distribute questionnaires, 12% (n = 4) distributed the questionnaire themselves, and 27% (n = 9) used a combination of all three approaches (receptionist, practice nurse, CNSp). Overall 404 questionnaires were distributed among patients.

In total, 318 participants returned questionnaires (79%), and 315 completed them either fully or partially<sup>2</sup>. Only 233 (74%) of these had completed the questionnaire fully. Most of the 315 respondents were male (54%, n = 169), aged 45-64 years (45%, n = 141), or 65-79 years (35%, n = 109) (Table 1). Most participants seen by CNSp had T2DM (89%, n = 280). A small proportion had T1DM (8%, n = 25). Some were unsure which type of diabetes they had (3%, n = 9). Most participants had diabetes for over 10 years (31%, n = 99) or 1-5 years (31%, n = 96) and were treated by tablets

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<sup>2</sup>Two participants returned blank questionnaires; one participant only ticked the consent box and gender leaving the remainder blank

(61%, n = 191), with few on diet only management plan (9%, n = 29). See Table 2 for further detail on characteristics of the sample population.

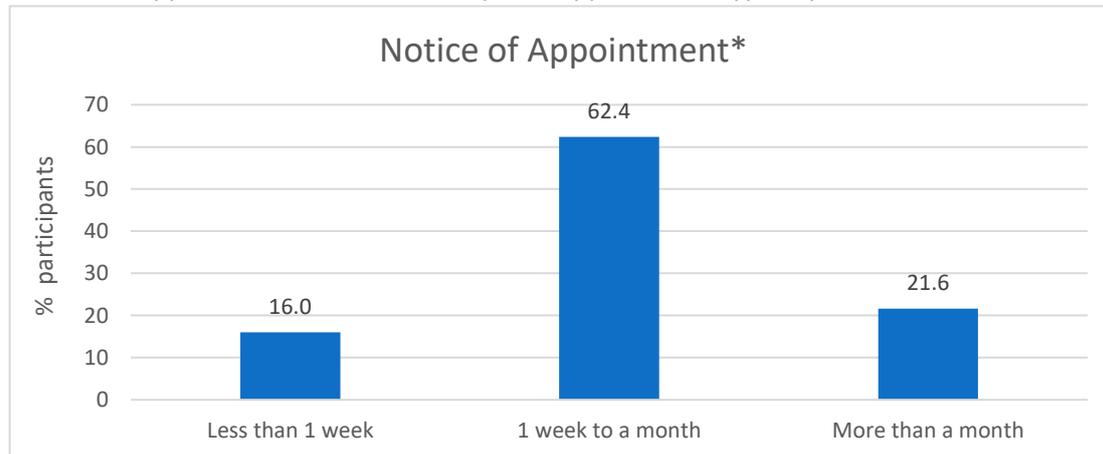
<b>Table 2: Characteristics of the sample population (n = 315)*</b>	
	<b>N (%)</b>
<b>Gender</b>	
Male	169 (54.3)
Female	142 (45.7)
<b>Age (years)</b>	
18-30	9 (2.9)
31-44	26 (8.4)
45-64	141 (45.3)
65-79	109 (35.0)
>80	26 (8.4)
<b>Type of diabetes</b>	
Type 1	25 (8.0)
Type 2	280 (89.2)
Unsure	9 (2.9)
<b>Length of time having diabetes</b>	
Less than 12 Months	42 (13.4)
1-5 Years	96 (30.7)
6-10 Years	61 (19.5)
Over 10 Years	99 (31.6)
Unsure	15 (4.8)
<b>Treatment</b>	
Controlled diabetes (i.e. diet)	29 (9.2)
Tablets	191 (60.6)
Tablets + Injections(Victoza, Bydureon, Trulicity)	49 (15.6)
Tablets + Insulin	59 (18.7)
Insulin Injections	25 (7.9)

*Table 2: Characteristics of the sample population*

\*Based on total number responding to each question. Numbers (%) missing differed across each variable: age, 4 (1.3%); gender, 4 (1.3%); type of diabetes, 1 (0.3%); length of time having diabetes, 2 (0.6%);

## Consultation

Most participants (84%, n = 241) were given more than one week notice of their appointment with the CNSp (Figure 1). Of those who responded to the question, the majority (99%, n = 302)<sup>3</sup> felt the notice of their appointment was satisfactory. The appointment typically lasted 30-45 minutes (Figure



2).

Figure 1: Notice of appointment

\*Based on total number who responded to the question; 28 (8.9%) did not answer this question

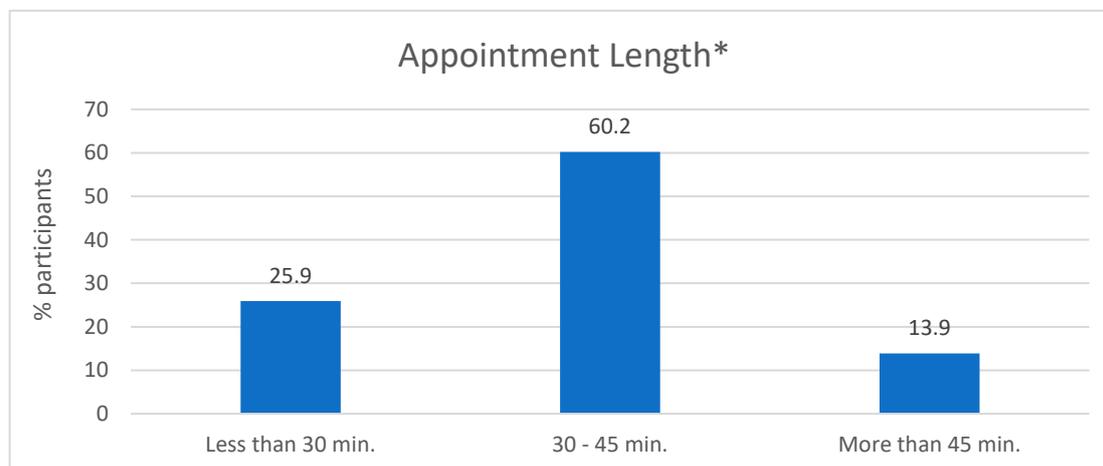


Figure 2: Appointment length

\*Based on total number who responded to the question; 41 (13%) did not answer this question

<sup>3</sup> 9 (2.9%) did not answer this question

## Foot care

The majority of participants (91.5%) reported that their feet were always or sometimes checked as part of their visit to the CNSp (Figure 3).

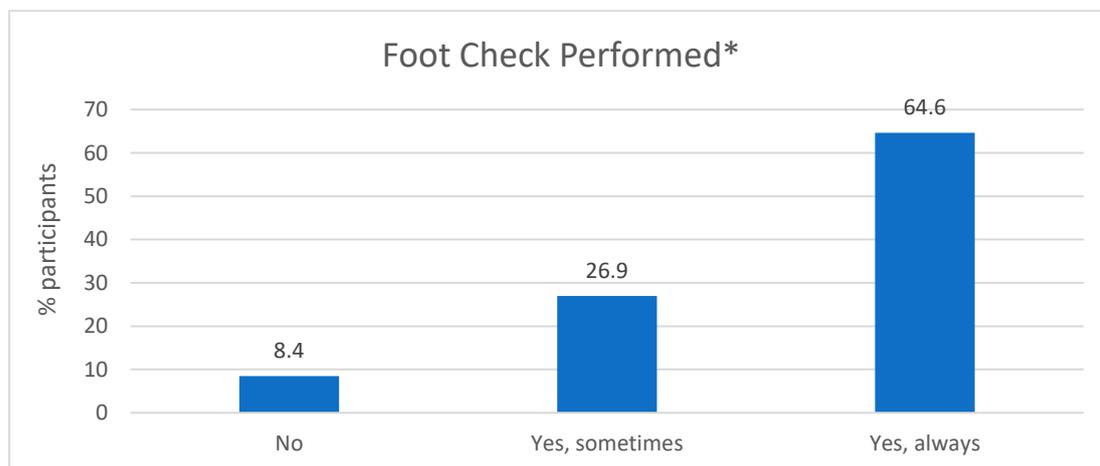


Figure 3: Foot check performed at the appointment with CNSp

\*Based on total number who responded to the question; 7 (2.2%) did not answer this question

## Experience of consultation

Almost all participants (97.8%, n = 306) felt that the CNSp explained their condition in a clear and concise way that could be understood (Figure 4). Most felt they had enough time to discuss their care and treatment with the nurse (98.4%, n = 313) (Figure 5), and that they always received answers they could understand (94.2%, n = 295) (Figure 6). The majority of participants (96.2%, n = 304) also felt they received the right amount of information about their condition (Figure 7), received enough information to manage their diabetes (93.5%, n = 288) (Figure 9) and were involved as much as they wanted to be in decisions about their care and treatment (97.1%, n = 298) (Figure 10).

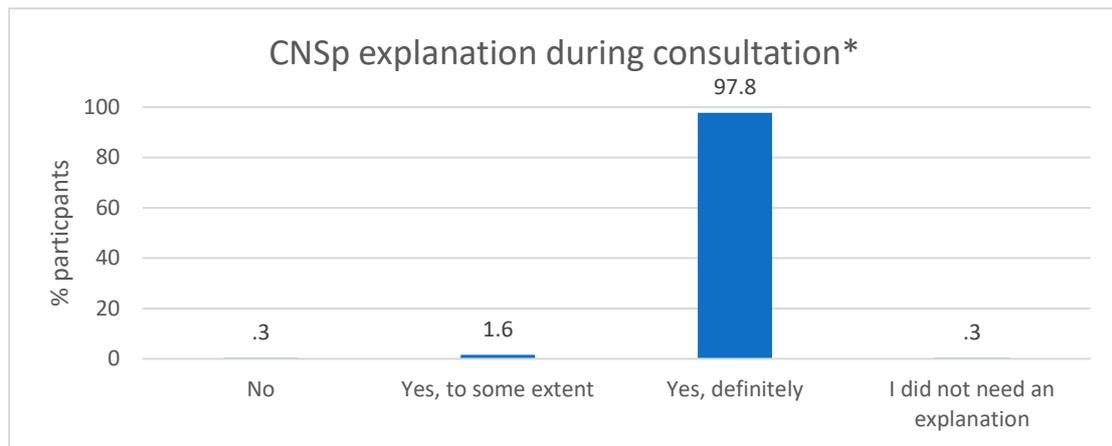


Figure 4: CNSp explanation during consultation was clear and concise

\*Based on total who responded to the question; 2 (0.6%) did not answer this question

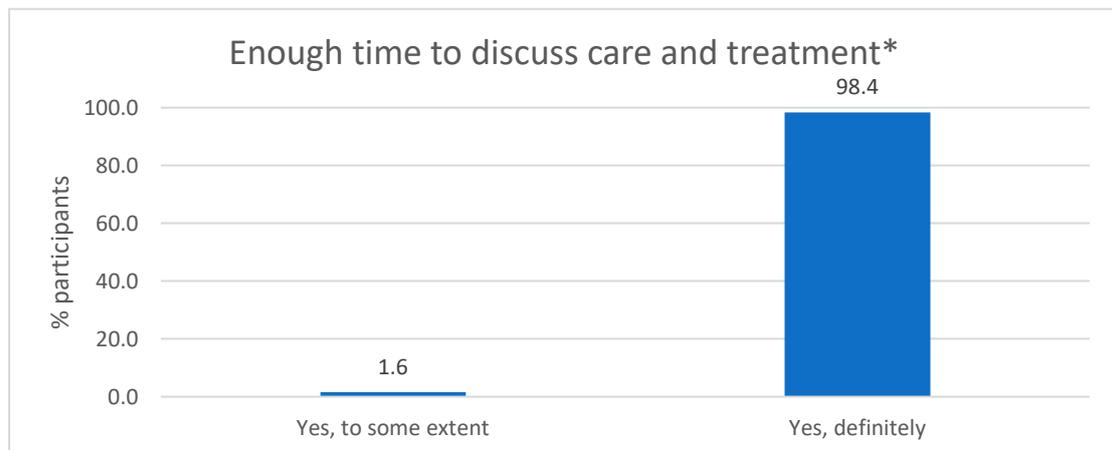


Figure 5: Enough time to discuss care and treatment with CNSp

\*Based on total who responded to the question; 2 (0.6%) did not answer this question

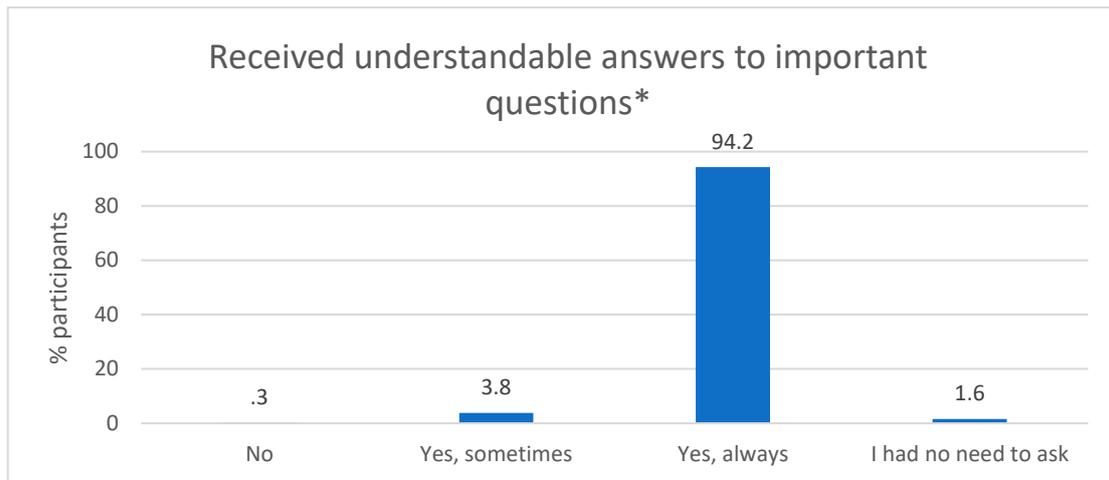


Figure 6: Received understandable answers to important questions asked of CNSp

\*Based on total who responded to the question; 2 (0.6%) did not answer this question

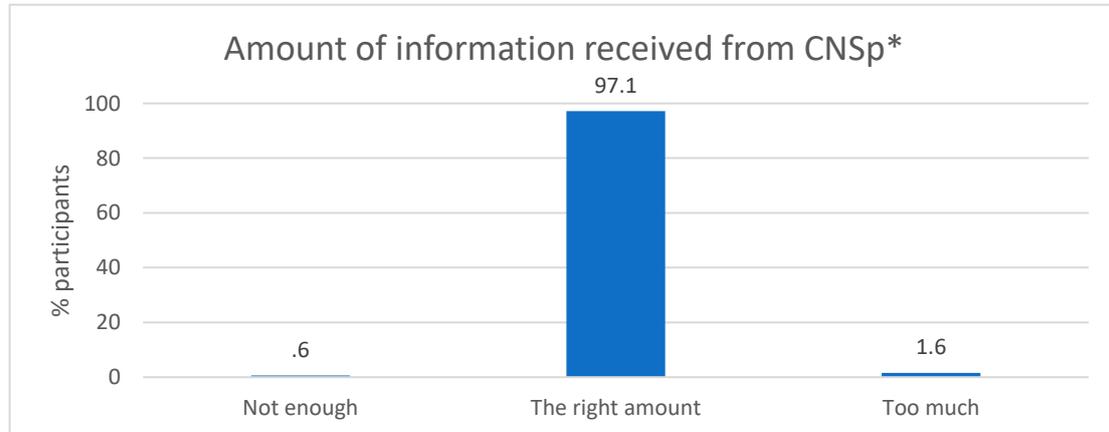


Figure 7: Amount of information about condition or treatment received from CNSp

\*Based on total who responded to the question; 2 (0.6%) did not answer this question

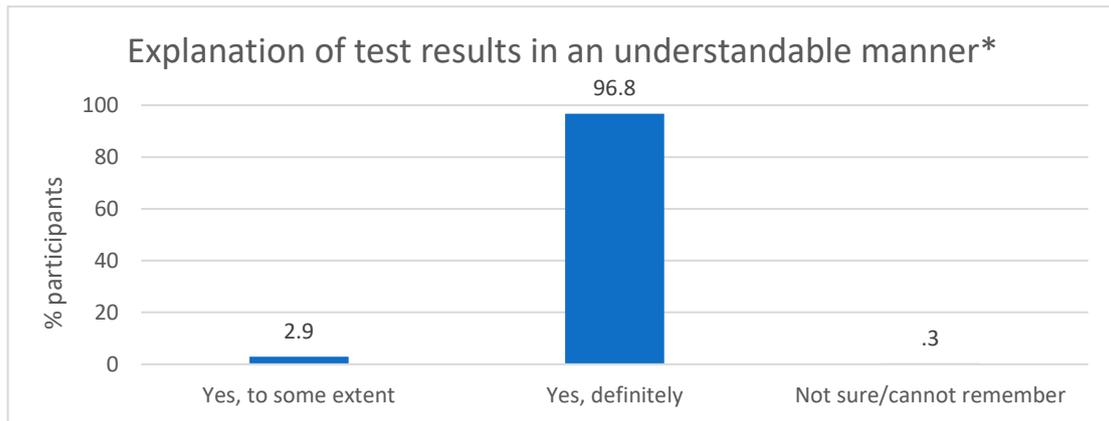


Figure 8: Explanation of test results in an understandable manner

\*Based on total who responded to the question; 7 (2.2%) did not answer this question

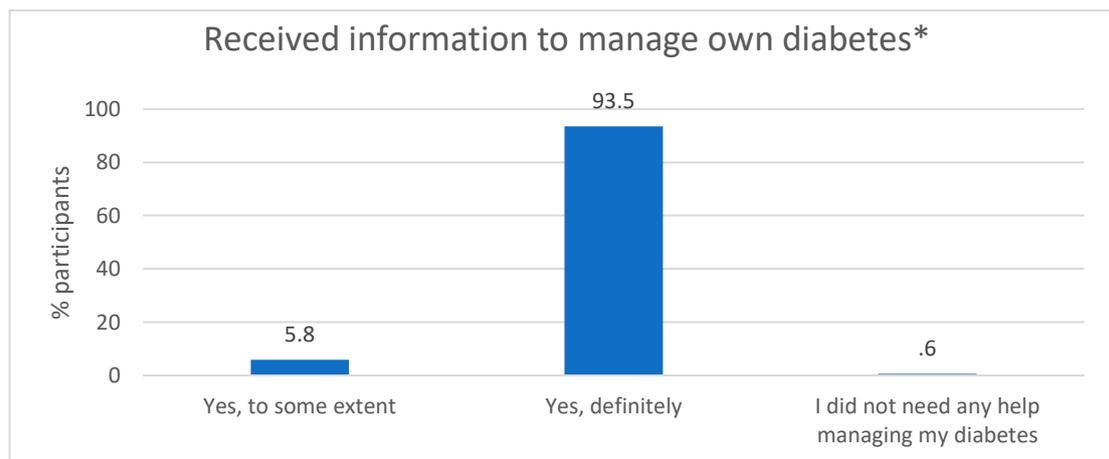


Figure 9: Received information to manage own diabetes\*

\*Based on total who responded to the question; 7 (2.2%) did not answer this question

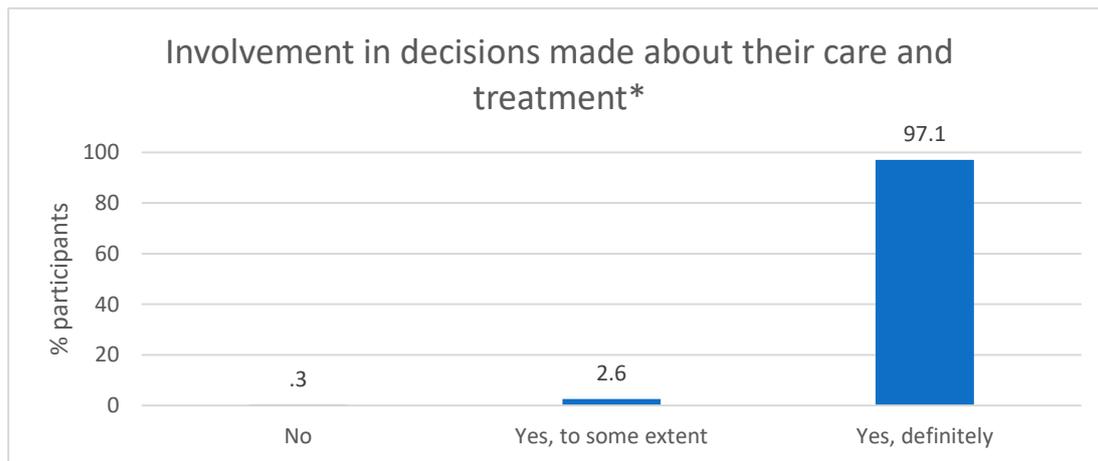


Figure 10: Involvement in decisions made about their care and treatment

\*Based on total who responded to the question; 8 (2.5%) did not answer this question

### Overall experience

Participants were asked to rate their experience with the CNSp service by indicating on a scale from one to ten, with ten being the best and one being the worst. Most participants rated their experience as very good (overall rating between nine and ten) (91%, n = 277) or good (overall rating between seven and eight) (8%, n = 25) (Figure 8). A small proportion (1%, n = 3) rated the service as fair to poor (overall rating between zero and six). Experience was similar across different age groups and between men and women (Figure 9).

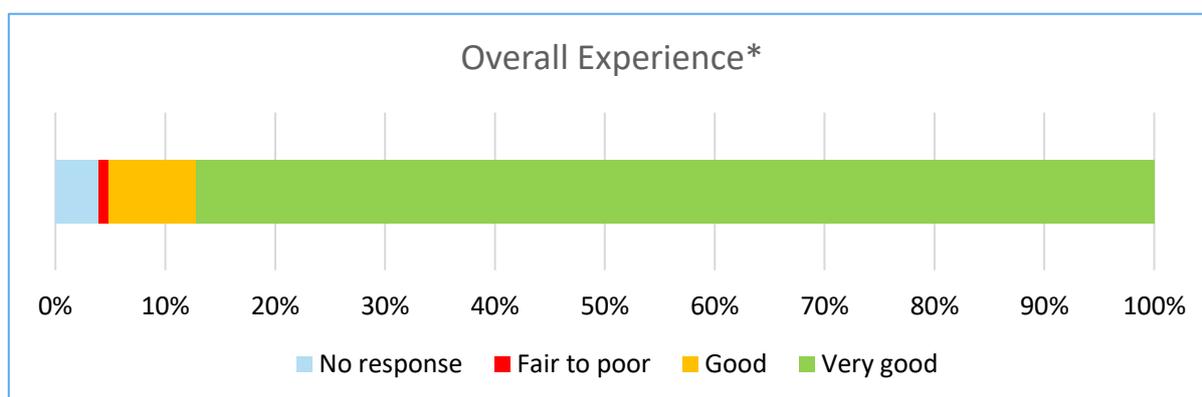


Figure 11: Overall experience

\*Based on total who responded to the question; 10 (3.2%) did not answer this question

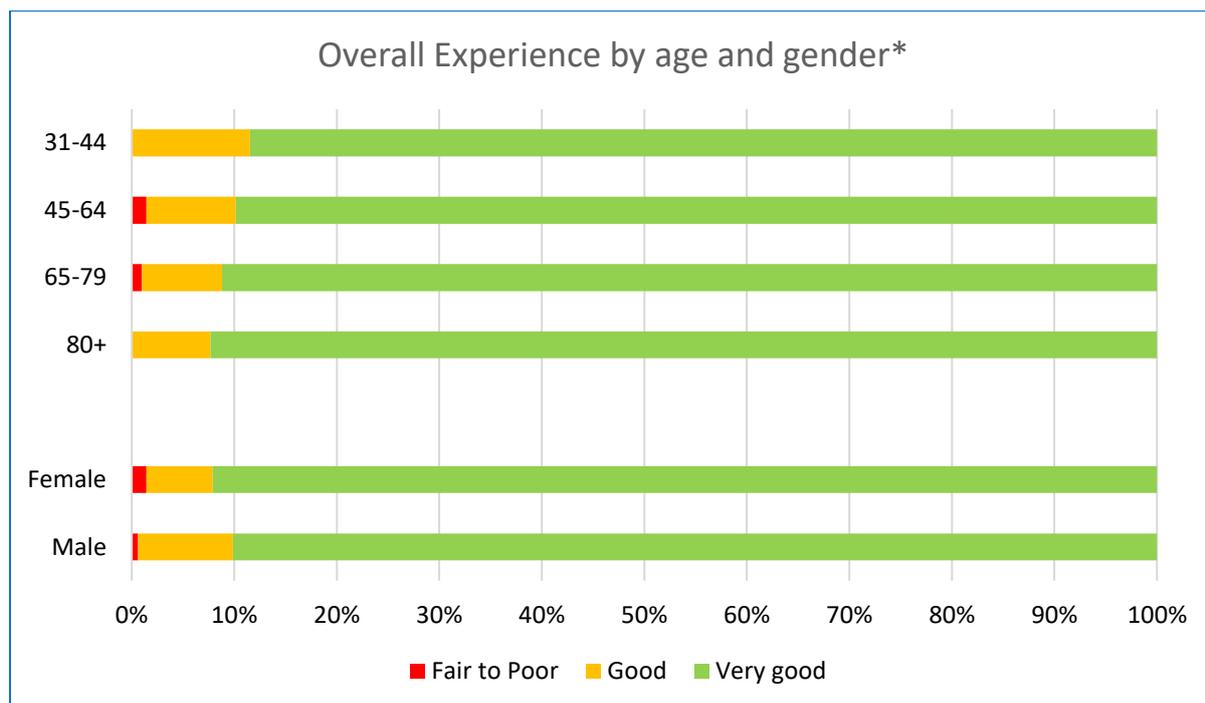


Figure 12: Overall experience by age and gender

\*Based on total who responded to the question; 7 (2.2%) did not answer this question

### Experience of the visit

When asked the open-ended question “Was there anything particularly good about your visit with the nurse?” 244 (77%) responded, giving positive feedback on the care they received from the CNSp consultation. Four themes were identified (See Table 3). Participants reflected on the quality of the communication between them and the CNS during the consultation, the manner and disposition of the CNSp, how the CNSp supported self-management, and other practical aspects of the service.

Table 3: Themes identified and supporting quotes	
<b>Communication</b>	<p><i>Very informative, answers my questions, given in simple English I could understand (#266)</i></p> <p><i>The nurse treated me like I am an intelligent human being. She gave me the feeling that I mattered. There was no rushing around (#229)</i></p>
<b>Manner</b>	<p><i>She is a very caring, patient, clear and easy to understand in the way she explains things, and she makes you feel at ease (#172)</i></p> <p><i>Very kind nurse. Knew what she was talking about. Very easy to talk to. Understanding (#299)</i></p>
<b>Supporting self-management</b>	<p><i>I now understand what is happening to my body and what it will take to keep me healthy (#215)</i></p> <p><i>I now understand how to look after my diabetes. She encouraged me to start exercising and praised me for my good blood results (#303)</i></p>
<b>Practical aspects</b>	<p><i>Beside home, seen on time- no waiting all afternoon. Everything checked including my feet. Nurse easy to talk to, good listener. Did not judge (#040)</i></p> <p><i>Very kind and helpful. A relief to have someone locally as it's very hard for me to get to the hospital [ ] miles away. I don't drive (#142)</i></p>

Table 3: Themes identified and supporting quotes

## Communication

Participants highlighted how the CNSp was good at explaining their condition and further treatments they may need to manage it (n = 38). They mentioned that the consultation was informative; they learned something new about their condition or the service they attended, or the CNSp helped them to understand their condition better (n = 55). Participant comments also reflected the *quality* of the communication; how the CNSp were 'easy' or 'good' to talk to, had the ability to communicate complex medical matters in a simple way, gave the participant time and made allowances for questions (n = 56).

*I was on one tablet and the nurse explained the side effects, which was never explained to me before in the hospital (#187)*

## Manner

Participants felt that the CNSp was very understanding of their needs as a patient (n = 18). They highlighted the CNSp' manner and disposition during the consultation (n = 75).

*Caring, helpful, obliging (#241)*

*I found the information was very clear and delivered in a caring and enthusiastic manner (#307)*

## Supporting self-management

Participants felt the CNSp helped them to manage their diabetes better (n = 26). Participants mentioned how the nurse organised further healthcare related appointments on their behalf to keep their condition under control (n = 6), and how the CNSp followed up with them after clinics via phone to check on their wellbeing (n = 3).

## Practicalities

Participants mentioned the short waiting times to access the service (n = 3) and how local the clinics were (n = 7). One participant commented on the cleanliness of the service.

*Much better to be near home in GP Surgery. No waiting for hours like hospital clinic. Checked everything- got feet done, got hour off work instead of full day (#85)*

## Discussion

This survey evaluated patient experience of Clinical Nurse Specialist Diabetes Integrated Care (CNSp) services across Ireland. The findings show that people report positive experience, reflecting favourably on different aspects of the consultation, including length, notice time, patient-nurse communication, understanding, and involvement in their care. When asked what they found good about their consultation, for the most part, people commented on the value of the service in terms of improving their understanding and management of their condition.

## Strengths and limitations

This survey is the first of its kind in Ireland to evaluate the patient experience of integrated diabetes nurse specialists. However, there are a number of study limitations which should be mentioned. It was not possible to determine whether those attending the CNSp were being managed in line with available guidance.<sup>34</sup> However, the participant profile suggests that CNSp are, for the most part, seeing people with T2DM and those with more complex needs; most people were on oral agents or insulin. The available information did not allow experience to be examined by diabetes complexity. On some occasions the survey could not be completed by people due to literacy and/or English language barriers. The readability of the survey may have been improved by external review by the National Adult Literacy Agency (NALA).<sup>35</sup> The small proportion who rated the service as fair to poor may have been the result of incorrect interpretation by patients; one patient, despite rating the service as fair, provided positive comments. The survey was sometimes distributed by the CNSp in practices where there was no receptionist or practice nurse available. Where participants had difficulty completing the survey, some CNSp offered assistance. Given the on-going relationship between patients and CNSp, these scenarios may have created the potential for social desirability

bias. Those responsible for distributing survey at the practice assessed participant eligibility. Therefore, the type of people approached with the survey may not have been standardised across practices and regions.

## Implications

The overall findings show that patients have a positive experience of the CNSp service, with people reflecting how the service improved their understanding and management of their condition. The results of the current study support the role of the integrated nurse specialist in the community. The longer appointment time may create an opportunity for dedicated discussion with patients about their condition. Most patients were very positive about the volume and nature of the information they received from the CNSp, reflecting on how complex information was communicated in an understandable way. If the role helps patients to better understand and manage their condition, as suggested by results of the current survey, this may lead to long-term benefits in terms of reduced inpatient admissions, and complications. There is existing evidence to indicate task shifting between professionals at different levels of expertise (e.g. GPs to nurses (practice nurse, nurse specialists, nurse practitioner specialised in diabetes<sup>36-42</sup>), or intermediary care provided by multidisciplinary teams including nurse specialist in diabetes<sup>36, 39</sup>, have delivered favourable results in terms of clinical outcomes<sup>39, 40, 42</sup>, inappropriate referrals to secondary care<sup>36</sup>, and outpatient attendances.<sup>41</sup> People with chronic diseases like diabetes have limited contact with the health professionals relative to the time spent at home, managing their condition on a day-to-day basis. Supporting self-management, improving patients' understanding of their disease, including necessary lifestyle changes and medications, is vital<sup>43</sup>, and has been prioritised in the Sláintecare report as key to develop a sustainable model of healthcare delivery.<sup>44</sup>

Foot care is an essential part of diabetes management. Regular checks are important to prevent longer term complications, including ulcers and amputations.<sup>45, 46</sup> According to the National Model of Care, foot checks of those at low risk should be performed annually in primary care.<sup>47</sup> However, these checks are not always performed<sup>48-50</sup>, and are less frequently performed by GP's compared to specialists.<sup>51, 52</sup> Most patients reported they had their feet checked during their appointment with the CNSp.

Nationally there has been on-going investment in strengthening of advanced nursing (clinical nurse specialist and advanced nurse practitioner) support in the community.<sup>53, 54</sup> The CNSp service is provided free of charge to patients and practices. However, not all practices, and patients, currently have access to the service.<sup>15</sup> There are approximately 2,932 (estimate from 2015) GPs nationally.<sup>55</sup> Based on data from the CNSp 2017 activity report, CNSp are attached to, and attend, a median of 18 practices per quarter, ranging from 11-33 practices across community health organisations. Given there are 30 full-time posts nationally, based on the upper limit this suggests 990 GPs (34%) could potentially have access to a CNSp. At the end of 2017 58% of CNSp reported being at capacity (i.e. they could not visit new GP practices).<sup>28</sup> There is also variation in the level of service, that is, frequency of practice visits, provided by CNSp service nationally. This may reflect a number of factors, including but not limited to, the number of CNSp in a region and local demand for the service, the location of referring GPs and time spent travelling.<sup>28</sup>

The current study suggests that patients view the CNSp service positively. However, further evaluation of the service is needed. Previous qualitative work with CNSp has indicated they may face initial challenges when establishing their service in GP practices<sup>15</sup>, and illustrates how CNSp have been innovative in setting up and driving the delivery of their service. However, this work was limited to the CNSp perspective.<sup>56</sup> Future research should consider exploring the perspectives of primary health care professionals, GPs and practices nurses, who access the service. Previous studies of integrated diabetes care have sought the views of different professionals<sup>57-60</sup>, yielding further

insight into whether and how the service is beneficial for patients and professionals in primary care and highlighting areas for improvement. It would also be valuable to determine the impact of the service on patient outcomes, for example, following up patients across practices before and after they access the CNSp service, and, if feasible, comparing to matched patients in practices over the same time period which do not have access to a CNSp.<sup>60</sup> Existing primary care diabetes initiatives which routinely collected patient-level data have reported some improvements in management over time, particularly in relation to the performance of key tests and checks.<sup>49, 50, 61</sup> While these routine audits illustrate the value of monitoring patient-level factors, they rely on manual data collection. In the absence of an electronic capture system, it is currently unfeasible for CNSp to collect biochemical patient data from practice records. While the data represented in this report indicates CNSp are delivering a local service which patients value, greater consideration needs to be given to how further evaluation of these posts can be supported and incorporated into ongoing service delivery.

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