

## **The International Consultation on Incontinence Questionnaires (ICIQ): an update on status and direction**

### **Abstract**

**Aims:** In its 22nd year, the International Consultation on Incontinence Questionnaire (ICIQ) project continues to promote its primary objective; the development and dissemination of patient completed questionnaires for the standardised, high quality assessment of urinary, bowel and vaginal symptoms. The paper gives an update on the ICIQ in the context of current scientific developments of PROM design and regulatory requirements, and plans are outlined for its future direction.

**Methods:** An online library of all questionnaires, including over 300 translations has been launched to facilitate access through a semi-automated registration system. The ICIQ project continues to update its protocol to meet current scientific standards and incorporate methodological advances within PROM development.

**Results:** Nineteen psychometrically validated patient reported outcome measures (PROMs) are published for use in clinical practice and research, including amongst others, a bladder diary, male and female lower urinary tract symptoms, long term catheter, pad use and bowel symptom questionnaires. The original ICIQ-UI Short Form for the assessment of urinary incontinence continues to be the most internationally used questionnaire and has been translated into over 60 languages. New questionnaires which are under development include the ICIQ-Underactive Bladder and ICIQ-Satisfaction. We anticipate the new website and online library will further facilitate the ease of dissemination and availability of the questionnaires for clinical practice and research.

**Conclusion:** The ICIQ continues to successfully achieve its primary objective. Going forward, a greater focus on promoting routine clinical use and the potential for electronic integration into databases and medical records is envisaged.

### **Introduction**

At the Scientific Committee Meeting of the first International Consultation on Incontinence (ICI), in 1998, a multidisciplinary committee was formed with the aim of the development and validation of a patient reported outcome measure (PROM) for use by patients with urinary incontinence. The ICI Questionnaire project was formally launched in 1999, to meet the requirement for universally applicable questionnaires for use in clinical practice and research (1,2). The result was the development of the ICIQ-Urinary Incontinence Short form (ICIQ-UI-SF) for the assessment of urinary incontinence and its impact on quality of life (3). The main aims of the ICIQ project were, and are, as follows:

1. To develop psychometrically validated questionnaires to evaluate symptoms and impact of dysfunction of the lower urinary tract, lower bowel and pelvic organ prolapse.
2. The adoption of existing questionnaires, that are psychometrically valid and complement the existing ICIQ questionnaires

3. To increase the use of patient reported questionnaires to standardise the assessment of lower urinary tract, lower bowel and pelvic organ prolapse and their impact on patients' lives.
4. To use the questionnaires to facilitate communication in different patient settings and different patient groups both in clinical practice and wider clinical research (4).

The first questionnaire to be developed, the ICIQ-UI SF, remains the most widely used and requested questionnaire and has now been translated into over sixty languages. Since the modular structure was finalised, the ICIQ has expanded to offer nineteen psychometrically validated patient reported outcome measures (PROMs) for lower pelvic dysfunction including incontinence (1), which includes amongst others, a bladder diary, male and female lower urinary tract symptoms (LUTS), long term catheter use, pad use and bowel symptom questionnaires. The purpose of the following paper is to provide an update on the ICIQ since its conception, in the context of current scientific developments of PROM design and regulatory requirements, and to outline plans for its future. The ICIQ project is based in the Bristol Urological Institute, at Southmead Hospital, Bristol, in the United Kingdom.

### **ICI Consultation 2017 and recommendations**

Since the first ICI in 1998 held in Monaco, there have been five consultations, resulting in six editions of a publication that comprehensively covers matters relating to the investigation and management of functional pelvic floor disorders. For each consultation, the executive committee appoints chairs who are responsible for defining the subject matter of their respective chapter, and forming an expert committee who collaborate to perform a systematic review of the relevant literature. During each consultation, the chairs of the individual committee make recommendations for the assessment and treatment of patients based on the committee findings. The committee 5B of the most recent 6<sup>th</sup> ICI was comprised of a number of experts on symptom and quality of life (QoL) assessment. As a result, the publication is a comprehensive review of the available PROMs related to the assessment of LUTS, bowel and vaginal symptoms and other important aspects of assessment and management, such as sexual function and quality of life (4). Each PROM received a grade, from A+ to C, based on the published evidence of the reliability, validity and responsiveness of the questionnaire. The grading of A was given if there is 'published evidence of validity, reliability and responsiveness to change' and is therefore 'highly recommended'. If there was additional evidence of content validity (i.e. evidence of patient involvement in the item development process) then the highest grade of Grade A+ was awarded. If there was less evidence of validity or reliability, a grading of B meant that it was 'recommended', and a grade C that the questionnaire had 'potential' but required further validation, before it could be recommended. All the ICIQ questionnaires except one are recommended with the grades of A or A+, by the 6<sup>th</sup> ICI (4). It should be noted that the grading of A reflects that historically, although patient were interviewed for the development of all ICIQ questionnaires, the evidence may not have been published or documented to current standards (2). Table 1 outlines the current PROMS that are included as part of the ICIQ modular questionnaire and information on their respective grades.

### **ICIQ development process and protocol**

The development of a PROM has become a rigorous and standardised, scientific process with the aim of providing evidence that the instrument is measuring what is intended, in a reliable and

reproducible way, and is appropriate to the target population for which it is designed. The process begins by establishing the clear rationale and reason for the initial development, before a series of sub-studies which are designed to demonstrate validity (accuracy), reliability (stability) and responsiveness to change (ability to measure change where it occurs) in the target patient population. The publication in 2009 of the United States FDA 'Guidance for Industry: Patient Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims' (5) and subsequent document 'Qualification Process for Drug Development Tools' (6) sets the scientific standard that is acceptable for the development of an outcome measure that can be considered by regulatory authorities for use in drug or device development. This is in-line with the methodological rigor that has been incorporated into ICIQ protocols. In particular, there is an emphasis on the inclusion of the patient perspective in the item development process (through concept elicitation interviews), and the documentation of the patient understanding of the instrument (through cognitive interviews) to ensure validity (7,8). This documentation is a key component of achieving regulatory approval of a PROM and is particularly essential if an instrument is intended to be used as an outcome measure in clinical trials (or to support labelling claims).

To ensure its continued success, the ICIQ continues to update its protocol to meet current scientific standards of PROM development. Newly developed questionnaires, that are included in the ICIQ portfolio, must have met current regulatory guidance and standards of documentation. As part of this, the process of establishing validity must include using patient involvement at each stage and subsequent psychometric testing, with details published in scientific journals, to allow the quality of development to be assessed. An overview of the current protocol used for the development of ICIQ questionnaires is given in Figure 1.

### **ICIQ modular structure**

As shown in Table 1 the core questionnaires comprise the questionnaires for the assessment of urinary incontinence, LUTS, vaginal symptoms and bowel symptoms including faecal incontinence. The additional health-related quality of life (HRQoL) questionnaires are used to assess additional specific issues that can arise as a result of symptoms, such as emotional or physical limitations. The questionnaires for sexual matters are specifically to evaluate the impact of LUTS, bowel and vaginal symptoms on this aspect, for both men and women separately. Specific patient group questionnaires are questionnaires that were developed for a particular patient population, so may only be used in the population for which they were designed, such as the ICIQ-CLUTS for assessing urinary symptoms in children (9). The available long-form questionnaires, ICIQ-MLUTS LF and ICIQ-FLUTS LF have additional items that may be of use for research studies, but have not been shortened or scored for the benefit of efficiency in clinical practice.

### **Questionnaires under development**

Questionnaires that are still in development include the ICIQ-Neuro Bowel and the ICIQ-Cog for the assessment of impact and care of incontinence in cognitively impaired adults (10). The ICIQ-UAB continues its development, and has published evidence of content validity and initial subsequent psychometric testing (11,12). It is currently undergoing further testing as the primary outcome measure within a proof of concept phase II clinical trial. The ICIQ-Satisfaction is a questionnaire which covers aspects of patient satisfaction with experience, expectations and outcomes and has recently been tested in a post-surgical population of men after prostatectomy and has been

submitted for publication. After further testing, the intention is for the ICIQ-S to be widely applicable for use in clinical practice and research after urological and gynaecological surgical procedures. A further questionnaire to assess patient satisfaction after urological investigations (e.g. urodynamics) is also under development.

### **The ICIQ website and online library**

Since 2004, the website [www.iciq.net](http://www.iciq.net) has achieved successful widespread international dissemination of the ICIQ portfolio of PROMs. In 2019, a new website was launched where questionnaires and translations can be requested through a semi-automated system, increasing the accessibility of the questionnaires for use in academic research and clinical practice. A potential user is asked to complete a brief electronic request form and user agreement and then access to the ICIQ online library is given. Permission for the use of the questionnaires remains free of charge for small grant funded research, student projects and clinical use. Commercial and research organisations with nationally supported funding (e.g. NIH in the USA, and NIHR in the UK, or equivalent) are asked to pay royalties for permission to use the questionnaires and any monies raised are used to fund the not-for-profit research and the continuing development of the ICIQ questionnaires. The ICIQ twitter account (@ICIQ\_PROMs) has also been in operation since 2019, to boost the social media presence and further publicise the ICIQ. Updates can be shared on this platform whenever a new questionnaire or new translation is developed, including new publications that are of interest to followers and the urology, gynaecology, and coloproctology fields.

### **The use of the ICIQ in research**

A search on EMBASE revealed that as of October 2019 there have been over 3700 publications that mention the 'ICIQ' or the questionnaires. The average number of publications has increased from 5 per year in the period from 1999 until 2003, to 370 per year in the period from 2015-2019. We anticipate the improved presence of ICIQ online through the updated website, the ICIQ library, and social media will increase the dissemination of the questionnaires further, and continue the uptake of the ICIQ both in clinical practice and research.

### **Translations**

The ICIQ has a large library of over 300 translations for its questionnaires. All of the available translations for each of its questionnaires are listed on the ICIQ website. If a translation is not available then the ICIQ team are happy to collaborate with the development of the new translation and will help with the process. There is a standard protocol for the translation of ICIQ questionnaires. In summary, a native speaker of the target language first produces the new language version, followed by a back translation by a native English speaker. This is reviewed by one of the ICIQ team and any differences between the original English and the back translation are reconciled. The new language version is then tested with a small number of the target language population to check its validity. The ICIQ group retains copyright for any translations that are produced, and the distribution is managed centrally through the ICIQ website.

### **ICIQ scoring**

The scoring of the ICIQ questionnaires is statistically derived by employing factor analysis methods to ascertain groups of items that are related to each other: each group is termed a domain. For

example, the ICIQ-MLUTS has a 'voiding' domain which relates items that record the presence and frequency of hesitancy, straining, strength of urinary stream, intermittency, sensation of incomplete emptying. A 'voiding' score can then be calculated by simply totalling up the score for each of these items (13). These may be used to compare scores over time, or between groups of patients. There is a part 'b' to each of the symptom items which asks "how much does this bother you?". This part of the item is not scored, but the user may use this to review which of the symptoms are of most concern to the patient and to target their management to the most bothersome symptoms. Detailed scoring instructions for all the questionnaires may be found on the ICIQ website or by request to the ICIQ development team.

### **Score interpretation**

A common question about the questionnaires is 'what does a particular score actually mean?'. For some questionnaires, studies have been carried out to establish bands of severity, for example, the ICIQ-UI SF (range 0-21) is given four scoring categories: slight (1-5), moderate (6-12), severe (13-18) and very severe (19-21) (14). A recent study has also ascertained scoring bands for the ICIQ-MLUTS (range 0-44: mild (0-16), moderate (17-25) and severe (26-44) (15). A minimally important difference (MID) is available for some instruments which provides further clarity. This represents the smallest change in scores between administrations detected by the questionnaire that the patient perceives as important, and might potentially lead to the patient or clinician to consider a change in management (16). For example, a change of score of 5-12 points on the ICIQ-LUTSqol (formerly the King's Health Questionnaire) is deemed to be clinically significant (17). However, as there are multiple methods for determining MIDs and scoring bands, and it can vary for each target population, it should be noted that these should be interpreted carefully. During questionnaire development, the ICIQ does not routinely assess MIDs or scoring categories for its questionnaires, but encourages further research to be carried out to empirically derive MIDs for its questionnaires.

### **Current PROM development methodology**

The ICIQ questionnaires have historically been developed using traditional classical psychometric methods. In addition to factor analysis, the use of item response theory (IRT) or Rasch methods can be complementary and maximise the content validity of a PROM (18), as modelling the item characteristics can provide additional information to make decisions on item removal, or to assess how well response options are working. IRT or Rasch methods allow items to be calibrated onto a common scale, or underlying construct (18,19). Item banks for SUI and OAB have recently been developed for using this methodology, by the PROMIS method (20). As for the ICIQ, the use of Rasch analysis alongside classical psychometric methods was used for the initial development of the ICIQ-Cog (10) and it is to be encouraged as another tool in the protocol for the development of existing and future ICIQ questionnaires.

### **The use of the ICIQ in clinical practice**

Despite their wide use in research, both as primary and secondary measures in clinical trials (21,22), PROMs are still relatively underused during routine clinical practice, in urology, gynaecology and coloproctology.. However, when asked about their use, health professionals are positive about their potential to inform their clinical decisions (23,24). Barriers identified to the successful integration of PROMs into clinical practice include fitting into clinical work patterns, patient data security concerns,

how to integrate data efficiently into IT or paperless systems, and how to process or use the data for patient benefit (23,25). There are no easy solutions to these issues (which are not specific to PROMs). However, the use of apps, web-based platforms or tablet computers may help the efficiency of data capture (26). We recognise the potential for the ICIQ questionnaires to be supplied and completed electronically and there is an ongoing drive in the UK NHS to 'go digital'. The integration of electronic PROMs into clinical practice is still rare in urology, however when achieved, it has been shown to increase clinician-patient discussions of incontinence in presenting patients (27). Although not yet available in electronic format, the scores of the ICIQ questionnaires have been shown to be equivalent when a questionnaire is administered electronically, by paper or over the telephone (28). Future work for the ICIQ project is to find ways of successfully integrating the ICIQ into clinical practice using digital means. A common vision of the purpose and rationale for collecting PROM data has to be shared, by patients, clinicians and other stakeholders if this goal is to succeed (23).

Patients attending the Bristol Urological Institute presenting with LUTS complete the ICIQ-FLUTS (29) or ICIQ-MLUTS (13) on paper, either before or during their first visit to the urological out-patient clinic, or the urodynamic unit. The responses are used during history taking and entered onto an online secure database for analysis. The ICIQ bladder diary is also used in the Uroflow clinic, as well as to assess the patient's suitability for sacral nerve device implantation. The patient records voided volumes, incontinence episodes, bladder sensations, fluid intake and pad use over three days (30). Other questionnaires can be used at initial assessment by patients presenting with LUTS at clinics. Condition specific ICIQ questionnaires such as the ICIQ-N or ICIQ-OAB may be used when a specific assessment of a condition in a particular population is required. Scores are calculated to allow the monitoring of patients over time, or to evaluate the effectiveness of interventions. The original ICIQ-UI SF is recommended in national guidelines (NICE clinical guideline 171) for the assessment of severity, impact and type of urinary incontinence at initial presentation.

## **Conclusion**

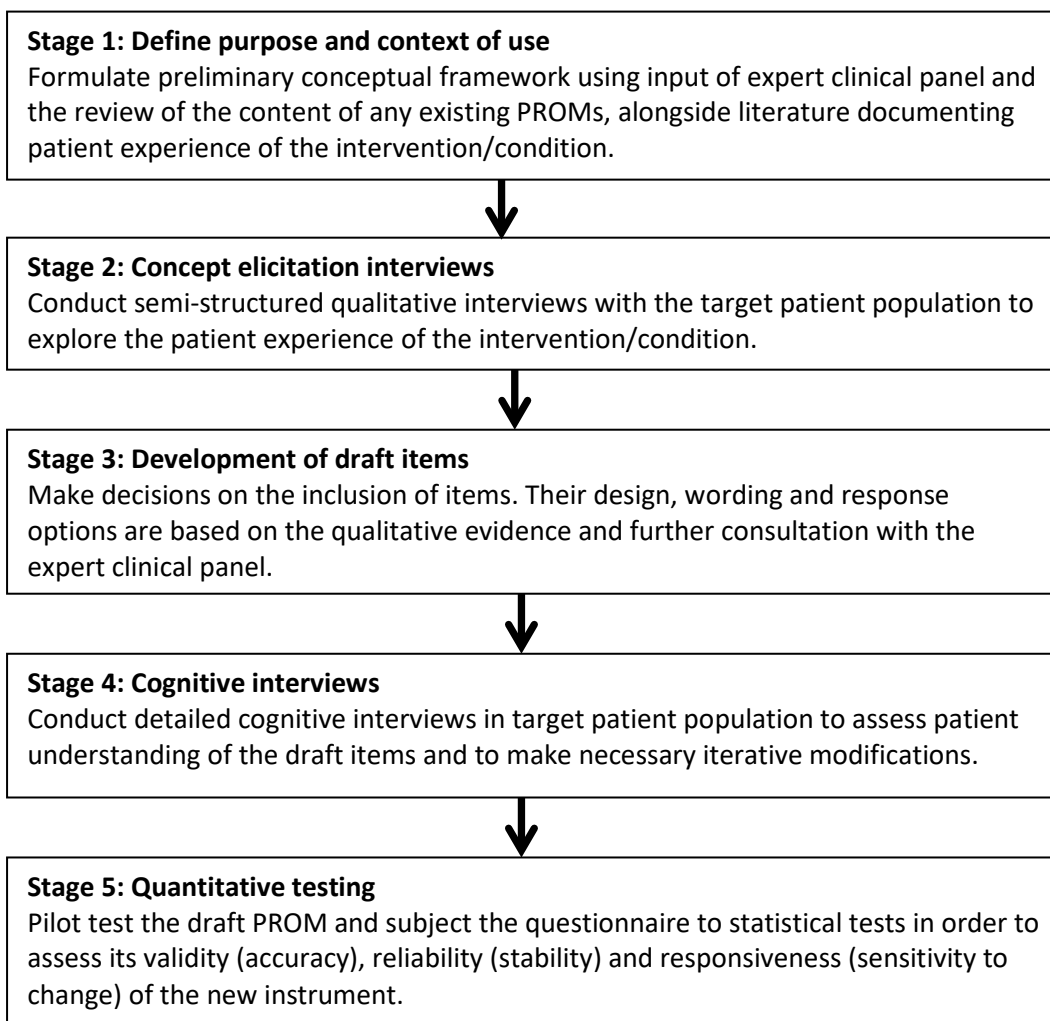
Now in its 22nd year, the ICIQ project continues to successfully achieve the main objectives of developing and disseminating robust patient completed questionnaires for research and clinical practice through a new website, an online library and by increasing social media presence. The ICIQ questionnaires are internationally used for research but going forward, a greater focus on promoting clinical use and the potential for their electronic integration into routine clinical practice is envisaged.

Condition	Core questionnaires				Post Treatment
	Recommended questionnaires	Optional questionnaires	HRQoL questionnaires	Sexual Matters	
Urinary Symptoms	Males: ICIQ-MLUTS(13) Females: ICIQ-FLUTS(29)	Males: ICIQ-MLUTS Long Form Females: ICIQ-FLUTS Long Form	ICIQ-LUTSqol(31)\$	Males: ICIQ-MLUTSsex Female: ICIQ-FLUTSsex	ICIQ-Satisfaction*
Vaginal Symptoms	ICIQ-VS(32)				
Bowel Symptoms	ICIQ-B(33,34)				
Urinary Incontinence	ICIQ-UI Short Form(3)		ICIQ-LUTSqol\$ ICIQ-UI SF	Males: ICIQ-MLUTSsex Females: ICIQ-FLUTSsex	
Prospective bladder events	ICIQ-Bladder diary(30)				
CONDITION	Specific patient groups				
	Recommended questionnaires		HRQoL questionnaires	Sexual Matters	
Nocturia	ICIQ-N		ICIQ-Nqol(35)\$	Males: ICIQ-MLUTSsex Females: ICIQ-FLUTSsex	
Overactive Bladder	ICIQ-OAB		ICIQ-OABqol(36)\$	Males: ICIQ-MLUTSsex Females: ICIQ-FLUTSsex	
Underactive Bladder	ICIQ-UAB*(11,12)				
Neurogenic	ICIQ-Neuro Bowel*				
Long Term Catheter			ICIQ-LTCqol(37)		
Children	ICIQ-CLUTS(9)				
Absorbent Pads			ICIQ-PadPROM(38)		

Inflammatory Bowel Disease	ICIQ-IBD				
Cognitively Impaired Adults	ICIQ-Cog*(10)				

Table 1. The ICIQ modular structure. The ICIQ-LUTSqol, ICIQ-B, ICIQ-Nqol and ICIQ-bladder diary all have an ICI Grade of A+. All others have an grade of A except the ICIQ-LTCqol which has a grade of B (4). The following modules were adopted as ICIQ modules with author’s permission: ICIQ-Nqol, ICIQ-OABqol, ICIQ-LUTSqol. \*These questionnaires are currently in development.

Figure 1. Summary of the ICIQ protocol for the development of questionnaires.







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