

## SPECIAL REPORT

# Questionnaires to Assess Chronic Itch: A Consensus Paper of the Special Interest Group of the International Forum on the Study of Itch

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**Chronic itch affects millions of patients worldwide and has a significant impact on quality of life. The assessment of itch and its associated effects is a significant component of clinical practice in itch management. Despite itch being a common complaint, there are few studies describing the use of structured questionnaires for evaluation and measurement of itch and its sensory and affective dimensions. The International Society of the Study of Itch (IFSI) has recently provided invaluable data on the use of visual analogue scales as an assessment tool for itch. However, it is clear that additional tools are needed to better assess the different dimensions of chronic itch and better tailor management. With this goal in mind, a Special Interest Group was initiated by members of IFSI to determine which of the various psychometric properties of itch questionnaires offer the greatest utility in the evaluation of chronic itch. This first consensus paper addresses what domains and structure of itch questionnaires need to be implemented to better assess chronic itch and guide therapy. *Key words: coping; itch; itch characteristics; itch measurement; pruritus; quality of life; questionnaires.***

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Chronic itch (CI) is defined as lasting 6 or more weeks according to the International Forum for the Study of Itch (IFSI) (1). It is one of the most prevalent problems within the health care system. A study of nearly 19,000 adults in Oslo, Norway found the prevalence of acute itch (“itch during the last 2 weeks”) in the general population to be 8.4% (2). In a recent study including more than 11,000 German workers seeking early skin cancer screening, CI was reported in 16.7% of this population (3). The only cross-sectional population-based study, investigating CI in the general population in 4,500 sub-

jects, estimated a 12-month prevalence at 16.4% and a life-time prevalence at 22% (4). This indicates a high burden of CI in society.

CI is the most common symptom in some dermatological diseases, such as atopic eczema, chronic urticaria and scabies, and is also a predominant symptom in psoriasis (5–9). CI is also a common symptom in systemic diseases, such as uremic patients with end stage renal failure that are on haemodialysis and in chronic cholestatic liver disease (9, 10). It is also commonly found in neuropathic diseases such as post-herpetic neuralgia (11) and in patients with psychiatric illnesses (12). The widespread nature of CI gains greater importance with the recent finding that CI has an impact on quality of life (QoL) on a par with chronic pain syndromes (13). Making comparisons of existing epidemiological studies is difficult due to differing methodology and a lack of standardized measures. Nevertheless, those existing show that CI represents a worldwide burden in the community and in specific patient populations (10).

Assessment of the various types of CI and its associated effects should be a central component of itch management. However, until recently specific guidelines for assessing itch did not exist. Moreover, there was a lack of studies examining the reliability and validity of various itch assessment tools. In 2008, IFSI established a special interest group (SIG) for the evaluation and harmonization of measurement tools for clinical trials. Since this time, two studies have clearly shown that the visual analogue scale (VAS) is the most reliable and valid itch assessment scale. This is closely followed by the numerical rating scale (NRS) (14, 15). However, it is clear from decades of chronic pain assessment that the use of a single measure does not ensure an adequate and comprehensive assessment of CI. But, assessments can become complex and burdensome to patients as the number of instruments utilized grows. An overabundance of administered measures may often complicate rather than clarify the assessment process. As new instruments are developed in this emerging field, each measure is individually evaluated and psychometric properties such as reliability and validity are established. Therefore, determining which of the

various tests displays the greatest utility in evaluation and responsiveness to change is critically important. Moreover, there are many cultural issues that need to be addressed. With these considerations in mind, a SIG comprised of itch researchers who have been developing, evaluating, and implementing itch questionnaires from 3 continents was initiated.

The purpose of this consensus article is (i) to highlight the need for the use of structured questionnaires in itch assessment, (ii) provide practicing clinicians and researchers in the field with an update on psychometrics recommended in a structured itch questionnaire, and (iii) to identify expectations and unmet needs to be addressed in future trials.

### WHY DO WE NEED A STRUCTURED ITCH QUESTIONNAIRE FOR PATIENTS WITH CHRONIC ITCH?

CI is a subjective and multidimensional sensation that includes functional, psychosocial and behavioural dimensions that are difficult to measure. Assessment of CI requires the documentation of qualitative aspects such as sensory and affective dimensions, coping and emotional characteristics and also quantitative characteristics of CI on severity, frequency, affected body surface as well as QoL and associated factors such as sleep disturbance, secondary skin changes (16). It is important to note that only relying on a single measure, such as the VAS, will not enable clinicians to sufficiently capture the efficacy of a treatment regimen. Using a multifaceted paradigm for itch assessment, success of treatment can be evaluated within numerous dimensions. As a result, subsequent therapy can be initiated to address specific areas of unmet needs. This approach is also useful in the design of clinical trials, which require numerous outcome measures to evaluate the response to CI treatment. This also includes the sensitivity to record changes over time.

### ITCH QUESTIONNAIRES – WHAT CAN THEY MEASURE?

Questionnaires deliver self-reported information regarding various aspects of CI. The different dimensions of CI that can be questioned about include the following previous questionnaires developed so far (5, 17–28):

- Localization: Where is the itch?
- Frequency of itch: How often does the itch occur (e.g. daily, weekly)?
- Duration of itch: How long has the itch been present (e.g. minutes, hours days)?
- Intensity: VAS, NRS.
- Sensory qualities: What does the itch feel like (e.g. pure itch, stinging, burning, mixed sensation)?

- Scratch response: E.g., rubbing, squeezing, pinching the skin.
- Opinion on origin: Patient's personal view.
- Affective dimensions: Bothering, unbearable.
- Aggravating or relieving factors: What makes the itch better or worse?
- Disability/impairment: How does the itch affects the patient's everyday life?
- Response to current and previous treatments: How effective have drugs and other treatments been?
- Coping: Itch specific coping styles.
- Itch cognitions: Catastrophizing and problem-focused coping.
- QoL.

Another important feature of itch questionnaires is their potential value as an aid in the differential diagnosis between various itch conditions. A recent study comparing itch characteristics in patients with atopic eczema and psoriatics found unique features of itch in each disease. For example, patients with atopic eczema reported higher itch intensity, suffering, and more extensive body involvement. In contrast, psoriatic patients had greater genital involvement and more embarrassment related to their itch (29). Therefore, descriptive patterns in standardized itch questionnaires have the potential to discriminate between various forms of CI.

### IMPORTANT ISSUES OF ITCH QUESTIONNAIRES

CI is multidimensional and assessment of CI needs to measure the different dimensions of CI. Specifically, both sensory qualities and unpleasant affective dimensions need to be addressed. A good itch questionnaire must establish validity through employing certain set off criteria that allow for both sensitivity and specificity. Repeatability variation in recording CI should be kept to minimum. The study of CI is complicated by multiple factors such as age, environment, level of education and literacy rate, social, cultural and psychological factors (10, 22, 23, 30) (Fig. 1). In particular, the impact of ethnicity on CI has received minimal attention. Itch intensity ratings are likely to differ between patients of varying ethnic and cultural backgrounds (30). Further, the distribution of underlying aetiologies causing CI varies substantially between countries (23). This can be explained by climate differences, characteristics of the health care system (with limited reimbursement for chronic systemic diseases), a reduced life expectancy and a reduced survival rate in chronic diseases (10, 23).

### WHAT DO WE EXPECT FROM A STRUCTURED ITCH QUESTIONNAIRE?

A structured questionnaire needs to be a reliable, validated and multidimensional measure with internal consistency for each dimension. A structured itch

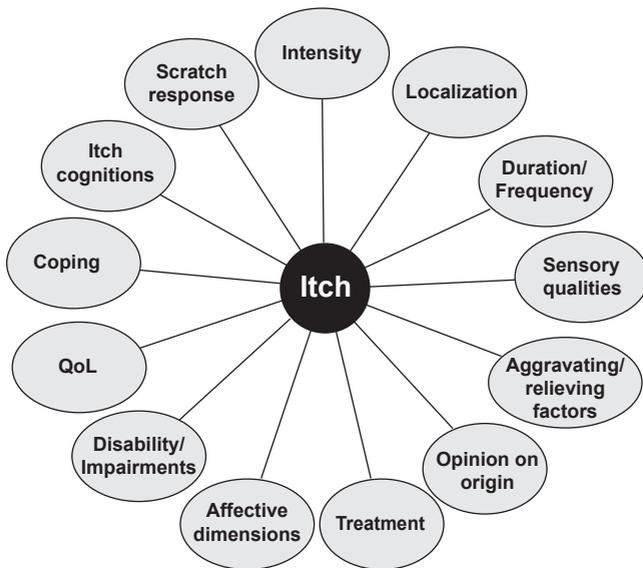


Fig. 1. Summarizes important factors that an itch questionnaire needs to address. QoL: quality of life.

questionnaire should consider the patients' perspective, the medical doctors' perspective and needs of various measurements in clinical trials. Considering patients, a questionnaire should be easy to understand and to complete and have a moderate length. A structured itch questionnaire should provide important information about relevant characteristics of CI for medical doctors and discriminate between the different types of CI. It should be useful as an outcome measure in clinical trials and should be able to detect changes in CI over time. In summary, designing a structured itch questionnaire should consider both, patients' and medical doctors' perspectives and the need to gather important medical information. In addition, it should serve as an outcome measure in clinical trials. Meeting all these needs is a substantial challenge. It was recently reported that good quality measurement, e.g. of patient-reported outcomes is a complex activity requiring considerable expertise and experience (31).

We suggest building two types of itch questionnaires, having a long and a short version of a structured itch questionnaire very similar to the long and short form of the McGill Pain questionnaire (32). The modules could be designed to collect various aspects of CI. It is quite clear that there are multiple dimensions of CI that can differ between disease states and types of CI and there are other factors and symptoms that may impact each type of CI. Further work will be needed to establish all this.

## CONCLUSIONS AND FUTURE WORK

The Special Interest Group (SIG) on questionnaires is an interdisciplinary team aiming to provide a template for questionnaires that could be used in different arrangements and modular configurations depending on

the underlying diagnosis. Future studies should focus on disease- and population-specific questionnaire validation.

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## REFERENCES

1. Ständer S, Weisshaar E, Mettang T, Szepietowski JC, Carstens E, Ikoma A, et al. Clinical classifications of itch: a position paper of the International Forum on the Study of Itch. *Acta Derm Venereol* 2007; 87: 291–294.
2. Dalgard F, Svensson A, Holm JO, Sundby J. Self-reported skin morbidity in Oslo. Associations with sociodemographic factors among adults in a cross-sectional study. *Br J Dermatol* 2004; 151: 452–457.
3. Ständer S, Schäfer I, Phan NQ, Blome C, Herberger K, Heigel K, et al. Prevalence of chronic pruritus in Germany: results of a cross-sectional study in a sample working population of 11,730. *Dermatology* 2010; 221: 229–235.
4. Mattered U, Apfelbacher CJ, Loerbroks A, Schwarzer T, Büttner M, Ofenloch R, et al. Prevalence, correlates and characteristics of chronic pruritus: a population-based cross-sectional study. *Acta Derm Venereol* 2011; 91: 674–679.
5. Dawn A, Papoiu ADP, Chan YH, Rapp SR, Rasette N, Yosipovitch G. Itch characteristics in atopic dermatitis: results of a work-based questionnaire. *Br J Dermatol* 2009; 160: 642–644.
6. Yosipovitch G, Ansari N, Goon A, Chan YH, Goh CL. Clinical characteristics of pruritus in chronic idiopathic urticaria. *Br J Dermatol* 2002; 147: 32–36.
7. Yosipovitch G, Goon A, Wee J, Chan YH, Goh CL. The prevalence of clinical characteristics of pruritus among patients with intensive psoriasis. *Br J Dermatol* 2000; 143: 969–973.
8. Krueger G, Koo J, Lebwohl M, Menter A, Stern RS, Rolstad T. The impact of psoriasis on quality of life: results of a 1998 National Psoriasis Foundation patient-member-ship survey. *Arch Dermatol* 2001; 137: 280–284.
9. Zucker I, Yosipovitch G, David M, Gafter U, Boner G. Prevalence and characterisation of uremic pruritus in patients undergoing hemodialysis: uremic pruritus is still a major problem for patients with end-stage renal disease. *J Am Acad Dermatol* 2003; 49: 842–846.
10. Weisshaar E, Dalgard F. Epidemiology of itch: adding to the burden of skin morbidity. *Acta Derm Venereol* 2009; 89: 339–350.
11. Oaklander AL, Bowsher D, Galer B, Haanpaa M, Jensen MP. Herpes zoster itch: preliminary data. *J Pain* 2003; 4: 338–343.
12. Mazeh D, Melamed Y, Cholostoy A, Aharonovitch V, Weizman A, Yosipovitch G. Itching in the psychiatric ward. *Acta Derm Venereol* 2008; 88: 128–131.
13. Kini SP, DeLong LK, Veledar E, McKenzie-Brown AM, Schaufele M, Chen SC. The impact of pruritus on quality of life: the skin equivalent of pain. *Arch Dermatol* 2011; 147: 1153–1156.
14. Phan, NQ, Blome C, Fritz F, Reich A, Ebata T, Augustin M, et al. Assessment of pruritus intensity: a prospective study on validity and reliability of the Visual Analogue Scale (VAS), Numerical Rating Scale (NRS) and Verbal Rating Scale (VRS) in 471 chronic pruritus patients. *Acta Derm Venereol* 2012; 92: 502–507.
15. Reich A, Heisig M, Phan NQ, Taneda K, Takamori K, Takeuchi S, et al. Visual Analogue Scale: Evaluation of the instrument for the assessment of pruritus. *Acta Derm*

- Venereol 2012; 92: 497–501.
16. Yosipovitch G. Itch questionnaires as tools for itch evaluation. In: Yosipovitch G, Greaves MW, Fleischer AB, McGlone F, editors. Qualitative aspects in addition to this assessment. *Itch Basic Mechanisms and Therapy*. Marcel Dekker 2004: 169–182.
  17. Ehlers A, Stangier U, Dohn D, Gieler U. Cognitive factors in itching: development and validation of a questionnaire. *Verhaltenstherapie* 1993; 3: 112–119.
  18. Kawashima M, Tango T, Noguchi T, Inagi M, Nakagawa H, Harada S. Addition of fexofenadine to a topical corticosteroid reduces the pruritus associated with atopic dermatitis in a 1-week randomized, multicentre, double-blind, placebo-controlled, parallel-group study. *Br J Dermatol* 2003; 148: 1212–1221.
  19. Darsow U, Mautner VS, Bromm B, Scharein E, Ring J. The Eppendorf Itch Questionnaire. *Hautarzt* 1997; 48: 730–733.
  20. Darsow U, Scharein E, Simon D, Walter G, Bromm B, Ring J. New aspects of itch pathophysiology: component analysis of atopic itch using the „Eppendorf itch questionnaire“. *Int Arch Allergy Immunol* 2001; 124: 326–331.
  21. Yosipovitch G, Zucker I, Boner G, Gafter U, Shapira Y, David M. A questionnaire for the assessment of pruritus: validation in uremic patients. *Acta Derm Venereol* 2001; 81: 108–111.
  22. Kupfer J, Keins P, Brosig B, Darsow U, Diepgen TL, et al. Development of questionnaires on coping with disease and itching cognitions for children and adolescents with atopic eczema. *Dermatol Psychosom* 2003; 4: 79–85.
  23. Weisshaar E, Apfelbacher CJ, Jäger G, Zimmermann E, Bruckner T, Diepgen TL, Gollnick H. Pruritus as a leading symptom: clinical characteristics and quality of life in German and Ugandan patients. *Br J Dermatol* 2006; 155: 957–964.
  24. Weisshaar E, Ständer S, Gieler U, Mattered U, Darsow U. Development of a German language questionnaire for assessing chronic pruritus (AGP-questionnaire). Background and first results. *Hautarzt* 2011; 62: 914–927.
  25. Majeski CJ, Johnson JA, Davidson SN, Lauzon GJ. Itch Severity Scale: a self-report instrument for the measurement of pruritus severity. *Br J Dermatol* 2007; 156: 667–673.
  26. Desai NS, Poindexter GB, Miller Monthrop Y, Bendeck SE, Swerlick RA, Chen SC. A pilot quality-of-life instrument for pruritus. *J Am Acad Dermatol* 2008; 59: 234–44.
  27. Elman S, Hynan LS, Gabriel V, Mayo MJ. The 5-D-itch scale: a new measure of pruritus. *Br J Dermatol* 2010; 162: 587–593.
  28. Haest C, Casaer MP, Daems A, DeVos B, Vermeersch E, Van Steenberghe W et al. Measurement of itching: validation of the Leuven Itch Scale. *Burns* 2011; 37: 939–950.
  29. O’Neill JL, Chan YH, Rapp SR, Yosipovitch G. Differences in itch characteristics between psoriasis and atopic dermatitis patients: results of a web-based questionnaire. *Acta Derm Venereol* 2011; 91: 537–540.
  30. Tey HL, Yosipovitch G. Itch in ethnic populations. *Acta Derm Venereol* 2010; 90: 227–234.
  31. McKenna SP. Measuring patient-reported outcomes: moving beyond misplaced common sense to hard science. *BMC Medicine* 2011; 9: 86.
  32. Melzack R, Katz J. The McGill Pain Questionnaire: Appraisal and current status. In: Turk DC, Melzack R, editors. *Handbook of Pain Measurement*, 2nd edn. New York: Guilford Press, p. 2001, 35–52.