

Identification of needs of Pigmented Villonodular Synovitis (PVNS) patients using online bulletin board (OBB)

Nigel Cook¹, Kyle Landskroner¹, Susann Walda², Olivia Weiss², and Vikrant Pallapotu³

¹Novartis Pharma AG, Basel, Switzerland; ²GfK Health, Basel, Switzerland;

³Novartis Healthcare Pvt. Ltd, Hyderabad, India

Background

- PVNS is a very rare, benign proliferative tumor affecting the inner lining of synovial joints and tendon sheets
- Beyond symptom management, there is currently no drug treatment available, with surgery being the only option
- Scarce information on treatment needs of PVNS patients to inform drug development

Study Objectives

- To generate insights on PVNS patients' perspectives, both objective and emotional, related to their medical and therapeutic journey, experiences living with the disease, financial implications and future therapeutic needs
- To evaluate suitability of the Online Bulletin Board methodology for qualitative insight gathering with rare disease patients across 3 countries


Online Bulletin Board (OBB) - Methodology

Study Design

- 11 patients UK (n=4), US (4), Canada (3), aged 28-57, with PVNS for 2-27 years
- 7 patients had previously undergone arthroscopic surgery and/or synovectomy
- Recruitment was via physician referral; participant willingness was ensured
- OBB conducted for 4 days, followed by a 1.5 hour group telephone discussion

Patient Online Bulletin Board - Benefits

- Allows participants to comprehensively answer pre-defined questions
- Each participant can then respond to posts of other participants
- Discussion was structured & moderated but allowed for asking follow-up questions to probe deeper, check commonalities across the group
 - *Anonymous*
 - *Overcomes geographic restrictions*
 - *Convenient for patients*
 - *Individual responses & group interaction*
 - *Text, pictures, polls, ranking exercises ...*



OBB is a suitable method that lends itself well to uncover rare disease patient insights, which might not be revealed in focus groups or telephone interviews

PVNS patients – research findings

Identified patient unmet needs



Pain constitutes a significant psychological & emotional burden; it impacts mobility and all activities of daily life, impacts sleep and daytime performance due to fatigue



- **Need for better pain management**
- **Pain and physical well-being impact emotional well-being**



Surgery (arthroscopy) provides only short-term relief but does not get rid of PVNS. Relapse rate is high and pain may be worse than before the surgery. Repeat surgery can also lead to joint destruction, necessitating joint replacement



- **Disappointed with surgery**
- **Longing for an alternative, a therapeutic treatment option**



Orthopedic specialists / surgeons predominantly manage PVNS patients



A big financial impact on patients, their families and on the health care systems

- **In conclusion, PVNS patients would benefit greatly from a drug treatment (an alternative to surgery), which can reduce pain & stop/delay relapses**

A cure is the ultimate outcome that they of course hope for