



Phyllodes Patients' Perceptions of Care: Do They Trust Their Doctors?

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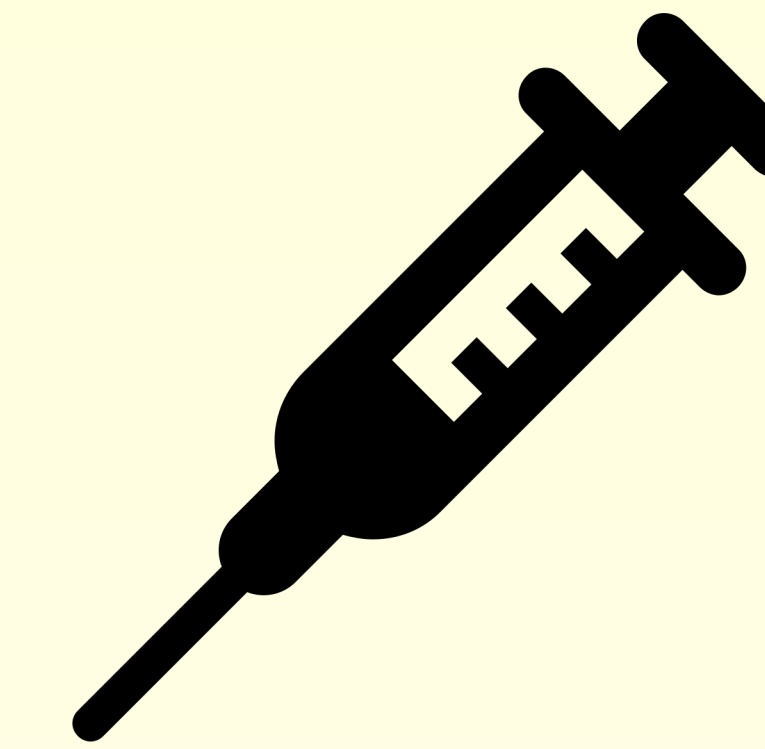
Background

- Phyllodes tumors account for <1% of breast tumors
- Management of phyllodes tumors varies widely
 - Benign/borderline phyllodes tumors may not require revision surgery even with positive surgical margins

Specific Aims

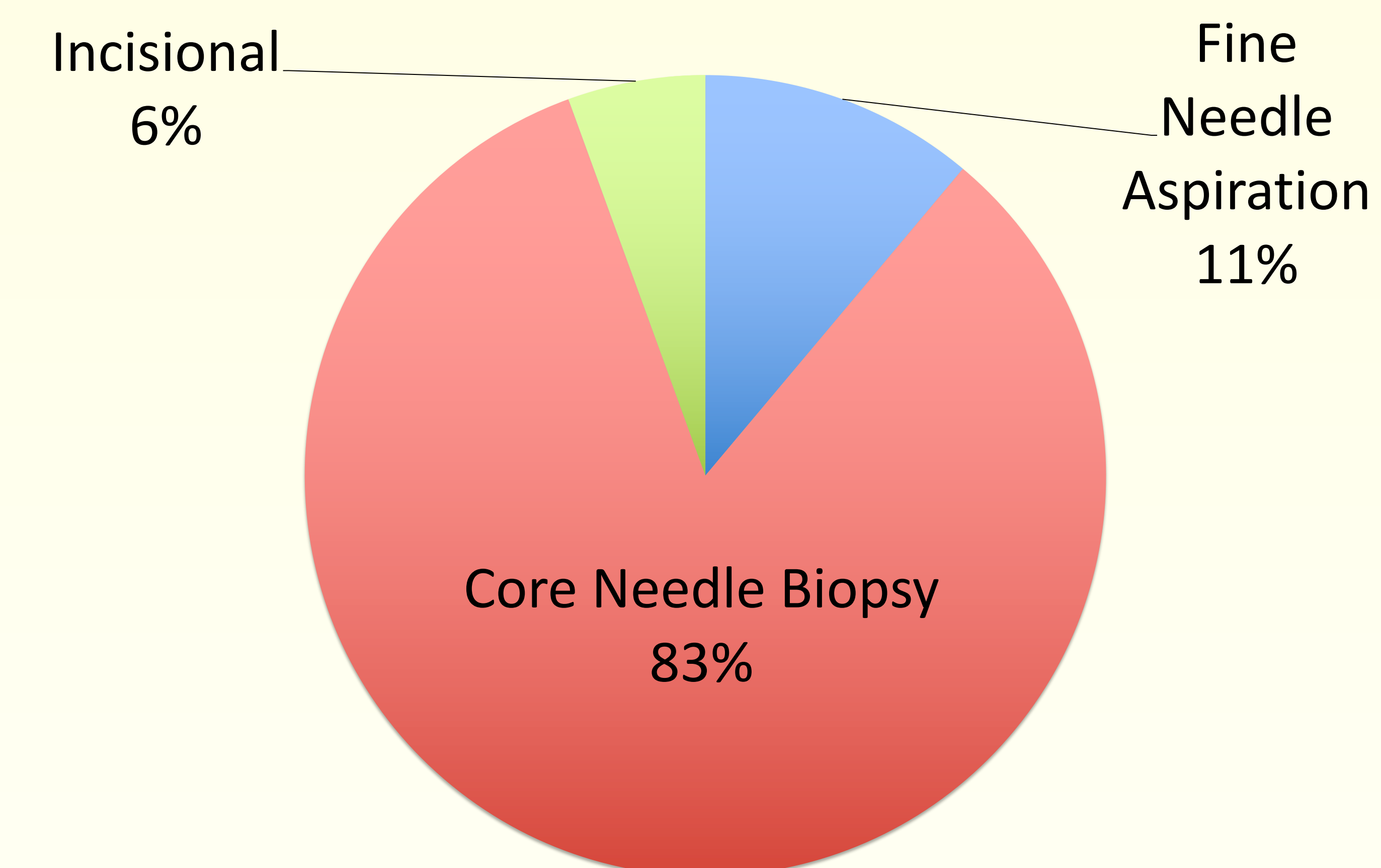
- Examine phyllodes management and outcomes across the world
- Study patients' perceptions of their care

Diagnosis and Management



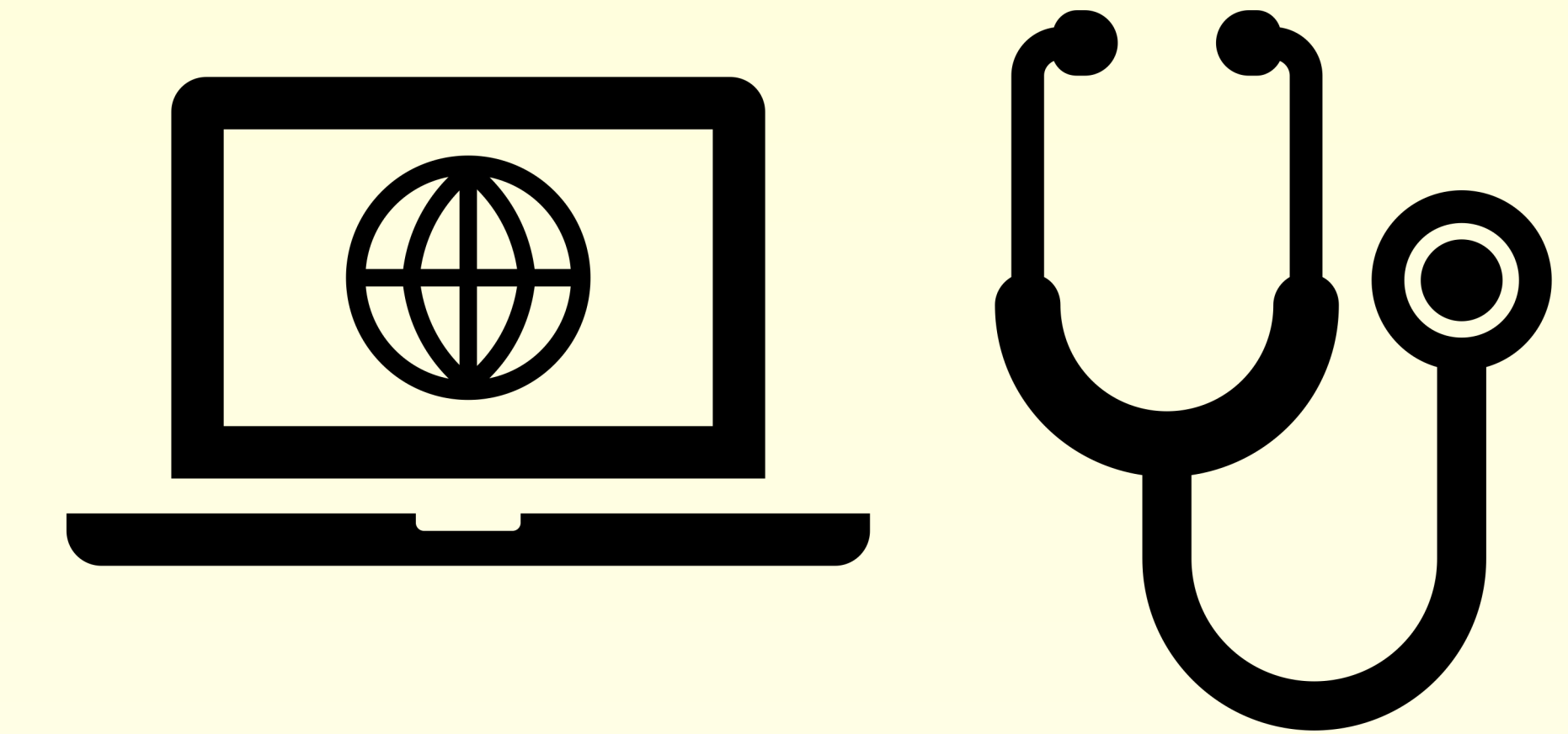
- 87% biopsied prior to surgery
- FNAs significantly less likely to diagnose phyllodes (43%, $p=0.028$)

Initial Biopsy



- 62% underwent lumpectomy, 30% mastectomy, & 8% excisional biopsy
- 50% of malignant tumors & 17% of borderline received radiation
- No patients received chemotherapy

Conclusions



Patients overwhelmingly trust other patients and the Internet over their doctors



- Patients express preference for more aggressive management
 - They prefer wider margins even for benign tumors

Future Directions



- Engage patients in building collaborations in care
- Conduct focus groups and interviews to better understand patient experiences and opinions
- Educational interventions can be targeted at combating common misconceptions about phyllodes tumors

Please email sli1@mgh.harvard.edu with any questions or comments

Data Collection



REDCap survey

Participants



Online phyllodes support group

93 women in 10 countries

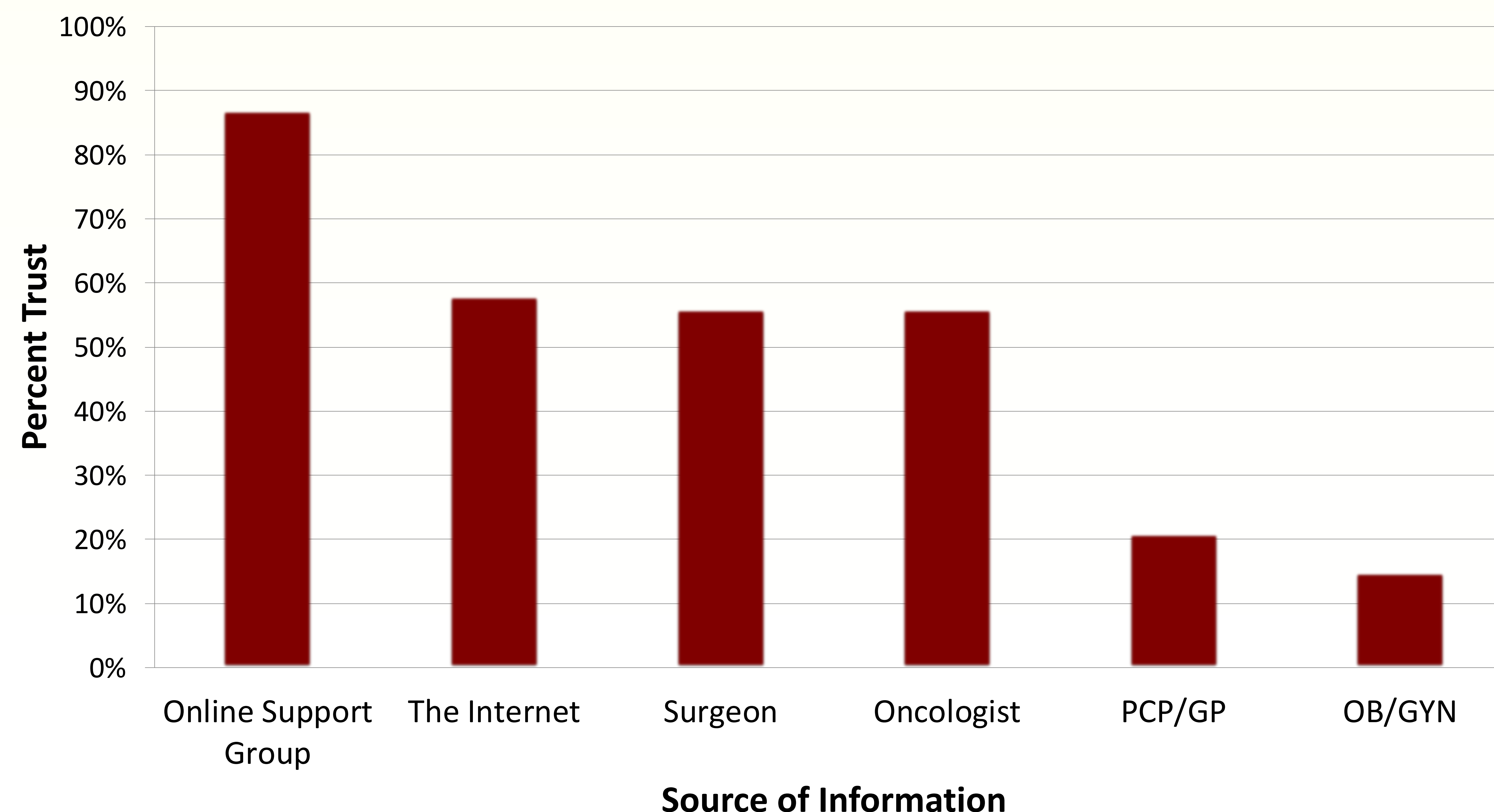
Demographics



Average Age at Dx: 44

32% benign, 26% borderline, 43% malignant

Patient Trust of Various Sources for Phyllodes Information



Outcomes/Perceptions



No significant association between recurrence and initial margin positivity ($p=0.059$) or tumor classification ($p=0.321$)

21% had recurrence
(83% local, 17% distant)

- 79% of patients thought surgical margins should be ≥ 1 cm for benign phyllodes tumors
- Most believed the follow up frequency for benign tumors should be every 6 months