

# BOLD UPDATES



Spring 2016

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## Hello BOLD Registry Participants!

Thank you for your continued interest in BOLD. The information gathered for BOLD/BOLDER will help both clinicians and patients to make better decisions for managing back pain.

We are pleased to share with you an update on what your participation in the BOLD registry is telling us. We also share with you early results of another research study that some of you participated in because you are part of the BOLD registry. This study is called SMARTER and is exploring how we can involve patients like you in setting priorities for back pain research. We hope you find this update helpful!

On behalf of the study team:



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## What is the BOLD Registry?

BOLD is a group of people over the age of 65 who have agreed to provide information about their back pain. We started BOLD in 2011 to address the problem that little is known about the long-term course of back pain among older adults, despite nearly one in three experiencing severe and disabling back pain. The BOLD Registry consists of 5,239 people who received health care from one of three healthcare systems (Kaiser Permanente, Northern California; Henry Ford Health System; and Harvard Vanguard Medical Associates). BOLD Registry participants shared information with us at 3 months, 6 months, one year, and 2 years after their first primary care doctor for their back pain.

## What Have We Learned from the BOLD Registry?

As a result of the information **you** and the other participants have shared with us about your back pain, we have been able to explore different aspects of how back pain is treated and how this information can have an impact on future health care practices! Summaries of some of our recent findings follow.

If you are interested in learning more about BOLD results, we have published 7 scientific articles to date. A list of current articles can be found at [www.backpainproject.org](http://www.backpainproject.org). To receive a copy of any of our articles, contact: [\(site contact info\)](#).

### ***Back Pain and Function Differs For Older Adults- Manuscript in preparation***

We examined 3 age sub-groups of BOLD registry participants (65-74, 75-84, and 85+ years of age) for changes in pain and function over time. We found that the older age groups had more functional limitations as a consequence of their back pain to begin with and don't improve in function over time as much as the younger age groups. This was different from pain, where pain levels remained similar over time across all age groups. In general, younger older adults were more likely to see an improvement in function than older seniors, but most people, regardless of age, did not see a dramatic improvement in pain over time. Furthermore, across age groups, complete resolution of functional limitations and pain happened only about a quarter (23%) of the time, and an even lower number (16%) had complete resolution of both functional limitations and pain.

**Conclusion:** Adults aged 85 and older were less likely to have substantial improvement in their back-related disability compared with adults between the ages of 65-84. Regardless of age, only one-quarter of adults 65 and older with a new episode of back pain had resolution of their back-related disability and pain after 24 months.

Previously published guidance has implied that most people will have a rapid recovery from an episode of back pain – and many researchers and physicians believe in and use this message as guidance in treating people with low back pain. We will need to disseminate the results of our

research to physicians and patients to make sure to set realistic expectations for back pain treatment and to encourage more research into providing more relief for older adults with back pain.

***BOLD Participants Involved in New Research: Prioritizing Topics for Research in Back Pain***

In 2014, the University of Washington BOLD team received an award from the federally funded Patient-Centered Outcomes Research Institute (PCORI) to conduct a research project to identify the most effective ways to involve patients in the beginning stages of medical research – specifically in identifying the research agenda and prioritizing research topics for action. Historically, the patient voice has been missing in this initial stage of research design. As a result, what matters most to patients may not have been reflected in research studies. The project team reached out to BOLD Registry participants at Kaiser Permanente, Northern California and Henry Ford Health System in Detroit, Michigan, to take part in a research study that would help us learn more about how to involve patients in identifying topics for research.

As a first step, we mailed BOLD Registry participants at Kaiser and Henry Ford a list of previously identified topics for back pain research. This list had been compiled by clinicians treating back pain patients. We asked BOLD participants at Kaiser and Henry Ford to tell us what they thought were the most important topics for research based on this previously generated list. Participants were also invited to add new topics to the list they thought were missing but important.

924 individuals participated, and the end result was a new list of research priorities, generated by patients with back pain. The final top priorities identified were:

1. What are the causes of low back pain?
2. What are the most effective self-care strategies for treating and managing low back pain?
3. What are effective tests to diagnose the causes of different types of low back pain?
4. What are the best strategies for putting research results into clinical practice?
5. Which physical health programs work best to help people experiencing different types of low back pain?
6. How can we best organize primary care services to become more effective in treating low back pain?
7. How can low back pain disability be reduced?
8. What patient characteristics and medical care factors predict a good response to treatment for low back pain?
9. What are the most effective ways to provide primary care patients with information?
10. What are the most effective strategies for improving physician communication and counseling skills when working with patients experiencing low back pain?

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11. How do different treatments for low back pain compare with regards to effectiveness and safety?

12. What role does weight control and exercise play in treating low back pain?

13. What role can Cognitive Behavioral Therapy, or counseling to help people manage stress, play in the treatment and management of low back pain?

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As a follow-up to this initial activity, we asked individuals if they were interested in taking part in a second phase of our work, by participating in an in-person focus group, completing additional mailed surveys, or participating in an online community. This phase of our work will help us further explore different ways to involve patients in identifying and prioritizing research topics allowing for more interaction between people. 932 BOLD Registry participants agreed to take part in one of these three second phase activities, and we are looking forward to continue working with BOLD members soon! We are conducting these activities now, so if you are part of the KP or HFHS health systems and indicated interest in participating in one of the activities, please be on the lookout for a letter from our team!

## **BOLD Publications**

The BOLD study team has published 7 articles as a result of the information that you shared with us. A full list of those publications can be found on the BOLD website at <https://backpainproject.org/publications.htm>. If you would like to receive a hard copy list of publications, please contact Sarah Lawrence ([lawreso@uw.edu](mailto:lawreso@uw.edu), 206-221-7453).

## **Your involvement is vitally important to us!**

Thank you again for your time and contribution to the BOLD Registry and SMARTER! Your involvement directly supports the BOLD Registry and research like SMARTER, that will help clinicians and patients make better decisions about managing back pain. By adding your voice, you are helping to confirm the importance of patient input in defining the usefulness of pain management practices that will improve the quality of care provided to patients like you.



**UW BOLD/SMARTER Team (from back left, clockwise):** Nancy Organ, Laurie Gold, Sean Rundell, Jerry Jarvik, Sofya Malashanka, Janna Friedly, Zoya Bauer, Sarah Lawrence, Danielle Lavalley, , Katie James. **Not pictured:** Bryan Comstock, Todd Edwards, Donald Patrick, Mary Scott, Anjali Truitt.