Web Report: Research use of electronic health records: patients' willingness to share information

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ABSTRACT

Importance: The widespread adoption of electronic health records (EHRs) has resulted in an unprecedented amount of health information of potential value to researchers. Because the ultimate success of this endeavor depends on building and maintaining public trust, patient input is critical to developing ethical approaches to research use of EHRs.

Objective: To examine how type of researcher and type of health information to be shared affect patients' willingness to permit researchers access to their EHRs.

Design: Semi-structured interviews, including card sort activities, in which participants were asked to sort a set of labeled cards into yes/no piles indicating their willingness to share EHR data under different circumstances.

Setting: Interviews were conducted in person between June 2015 and February 2016 in four diverse counties in the southeastern United States.

Participants: Recruitment letters were mailed to a random selection of adults in each county. English-speaking adults who had seen a healthcare provider in the past two years were eligible. Among those interested in participating, we used purposive selection to maximize demographic variability among the 120 interviewees.

Results: About half of participants said they would be willing to share *identifiable* data for research when given a broad yes/no choice. Regarding researcher type, participants were most willing to share with entities with which they had established relationships or that were broadly known; they were less willing to share with those for which they had no previous relationship or that, as a "type," comprised more heterogeneity. Regarding data type, participants were less willing to share sensitive than non-sensitive information with any type of researcher. Willingness to share genetic information, typically considered sensitive, was similar to that for non-sensitive data. When asked to make increasingly granular choices, participants' willingness to share often (but not always) increased.

Conclusions: Rather than imposing complex choices that may be unfeasible to operationalize, our results suggest that providing patients with examples of the range of researchers and data that may be involved may help to promote trust, transparency, and informed decision-making.

Table 1. Participant characteristics

	TOTAL		Cabarrus, NC		Durham, NC		Mingo, WV		Quitman, MS		p-value*
	n	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	
Total Participants	120	(100)	30	(25)	31	(26)	28	(23)	31	(26)	
Gender											
Men	44	(37)	10	(33)	14	(45)	9	(32)	11	(36)	0.73
Women	76	(63)	20	(67)	17	(55)	19	(68)	20	(65)	
Age group											
18-44	51	(43)	12	(40)	15	(48)	13	(46)	11	(35)	0.79
45-64	48	(40)	14	(47)	10	(32)	9	(32)	15	(48)	
65+	21	(18)	4	(13)	6	(19)	6	(21)	5	(16)	
Education											
Below high school (HS)	11	(9)	3	(10)	2	(7)	3	(11)	3	(10)	0.06
HS/GED/Vocational	31	(26)	4	(13)	7	(23)	11	(39)	9	(29)	
AA/Some College	32	(27)	7	(23)	5	(16)	9	(32)	11	(35)	
BA and Above	46	(38)	16	(53)	17	(55)	5	(18)	8	(26)	
Race											
Black or African American	39	(33)	4	(13)	14	(45)	1	(4)	20	(65)	<0.01
White	77	(64)	24	(80)	15	(48)	27	(96)	11	(36)	
Other	4	(3)	2	(7)	2	(6)	--	--	--	--	
Overall health [a]											
Poor/Fair	26	(22)	2	(7)	4	(13)	10	(36)	10	(32)	<0.01
Good	42	(35)	13	(43)	7	(23)	9	(32)	13	(42)	
Very good/excellent	52	(43)	15	(50)	20	(65)	9	(32)	8	(26)	

	TOTAL		Cabarrus, NC		Durham, NC		Mingo, WV		Quitman, MS		p-value*
	n	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	
Healthcare visits in past year [b]											
<=2 times	51	(43)	13	(43)	17	(55)	9	(32)	12	(39)	0.62
3-4 times	36	(30)	10	(33)	8	(26)	8	(29)	10	(32)	
5+ times	33	(28)	7	(23)	6	(19)	11	(39)	9	(29)	
Healthcare prohibited by cost? [c]											
No	89	(74)	23	(77)	26	(84)	21	(75)	19	(61)	0.24
Yes	31	(26)	7	(23)	5	(16)	7	(25)	12	(39)	
Have regular healthcare provider? [d]											
No	24	(20)	2	(7)	7	(23)	6	(21)	9	(29)	0.15
Yes	96	(80)	28	(93)	24	(77)	22	(79)	22	(71)	

[a] *Asked: In general, how would you rate your health?*

[b] *Asked: During the past 12 months, not counting times you went to an emergency room, how many times did you go to a healthcare provider to get care for yourself?*

[c] *Asked: Was there a time in the past 12 months when you needed to see a healthcare provider but could not because of cost?*

[d] *Asked: Do you have one healthcare provider (such as a doctor, nurse practitioner, physician assistant, or other health professional) that you see for most of your care?*

**p-values calculated using Fisher’s exact test; not adjusted for multiple comparisons*

Table 2. Proportion of participants willing to share health data, by researcher type

Type of Information	Own Physician n	Own Physician (%)	Own Healthcare Organization n	Own Healthcare Organization (%)	Other Healthcare Organization n	Other Healthcare Organization (%)	Government n	Government (%)	Commercial n	Commercial (%)
Identifiable data, in general	105	(88)	97	(81)	67	(56)	74	(62)	58	(48)
By data type:										
Demographic	111	(93)	102	(85)	88	(73)	91	(76)	78	(65)
Medication	109	(91)	102	(85)	86	(72)	83	(69)	76	(63)
Lifestyle	108	(90)	100	(83)	89	(74)	83	(69)	74	(62)
Past conditions & diseases	109	(91)	102	(85)	86	(72)	81	(68)	73	(61)
Ongoing conditions & diseases	107	(89)	98	(82)	84	(70)	82	(68)	70	(58)
Procedures & results	108	(90)	100	(83)	81	(68)	77	(64)	72	(60)
Genetic *	108	(90)	102	(85)	82	(68)	79	(66)	68	(57)
Substance abuse, history of *	100	(83)	92	(77)	76	(63)	73	(61)	67	(56)
Mental health *	101	(84)	93	(78)	74	(62)	69	(58)	61	(51)
Reproductive health *	98	(82)	91	(76)	71	(59)	66	(55)	58	(48)
Sexual health *	97	(81)	86	(72)	68	(57)	67	(56)	57	(48)

** Defined as sensitive by National Committee on Vital and Health Statistics*

Table 3. Selected quotes, sharing by researcher type

Own physician	Share	• [Your doctor] already knows your information and he can go ahead and use it for whatever study he needs to use it for. (M17)
	Not share	• There are very small communities, and so if your physician is not only your private physician but he's also using the information to conduct other studies, I'd be worried about how is that being done ethically. (M25)
Own healthcare organization	Share	• My information is already in their system, so it's still in-house. (D30)
	Not share	• I don't distrust necessarily [my HCO]; I just distrust the capability of them keeping [my identifiable information] secure, the fact that the computers are vulnerable. (D02)
Other healthcare organization	Share	• [Other HCOs] would be looking at general healthcare of a community … if my identifiable information helps with that, I'm fine with that. (CC24)
	Not share	• I just feel they may have some ulterior motive other than what they're telling you. (DC5) • [My HCO], they know more about me than anybody else and I trust them sufficiently, but [other HCOs] I say no because I don't know who the heck them folks are. (QC23)
Government	Share	• They do good research. And I trust the government. (C7) • You know, the government's gonna get [the information] anyway, whether you want them to or not. (Q10)
	Not share	• Everything is so easy to be hacked into right now and [the government has] been hacked a whole lot. (M11)
Commercial	Share	• I know [commercial research] is not going to benefit me first, but I'm willing to wait my turn, honey, because that's all I can do is just wait, wait, and be patient. It's not about being the first; sometimes you have to be the last sometimes. And the last might get the cookie jar, a full cookie jar, that's the way I see it. (Q23) • I have high blood pressure and if they can make a medicine that actually works – that would be, yea, I would care for that. (M11)
	Not share	• They shouldn't be able to get financial gain from my medical records. (C04)

Table 4. Selected quotes, reasons for sharing/not sharing data types

Reasons for Sharing	
Help advance science	• Because that kind of stuff can be used to identify problems that are directly applicable to the public good. (D13) • Well, maybe it helps somebody else. Even if they couldn't help me, maybe they could help somebody else down the line. (C31)
Data not sensitive	• [Lifestyle data is] just talking about records of exercise, my diet, my sleeping habits, stress levels. To me it's not really important. (D14) • I'd probably share [my genetic data] because what's it going to do? I don't feel like there are any risks with that, really. Well you're not ... you don't have my social security number. You don't have my name. That's not what I consider identifiable information. (C06)
Information already public	• I think that even researchers from commercial companies could get a hold of that information if they wanted to. It's probably pretty public … and people can understand your lifestyle just maybe even by looking at you they might know certain things. By talking to you for just a few minutes, they might learn a few things. You know, you can tell right away if someone's a smoker. You can visibly see if somebody is eating in unhealthy ways, things like that. (C08) • I feel like that's, in general, observable data. I think it's information that anybody can gather just by observing who you are, and I think that that's fine. (D30)
Trust	• I know my doctor, I know his wife, most of the people that work in that office is friends, so, yeah, I would share. (M02) • I just already feel really comfortable with the government. Because they already have some of my information anyway, so I wouldn't mind. (Q05)
Clean bill of health	• I don't use drugs or alcohol or anything so I wouldn't care. To me it's not a major privacy issue. (M19) • The sexual health information, being a man that has no related diseases or anything, clear of all that venereal stuff, I would say yes because in my later years maybe I might have a problem with erection, I would want maybe a better study to where they could get it to where I wouldn't have to take a little blue pill or something. (M02)

Reasons for Not Sharing	
Data too sensitive	• I've never had genetic testing. But that's something I feel would be really private, and I don't think I would want to share that with very many people. I don't even know what that might uncover. It's a closed book, and you have to walk in and open it up, and you don't know what you're gonna find in there. (C08) • You know people don't really care as much as they use to, maybe, but mental health still sounds like a sensitive issue (Q08)
Distrust	• When we think about making humanity better at the genetic level, you have to start asking who defines better and what happens to those people who are not defined as good enough. And in this state we forcibly sterilize people, which is understandably unpopular with those folks who are being forcibly sterilized, and a pretty blatant disregard for human rights. So, no, I don't think that genetic information is the government's business. (D13) • It goes back to trusting what is being done with the information, not really knowing the researchers like I will know my physician (D17) • I just don't really trust pharmaceutical companies; I feel like their motives aren't as good as other researchers as well. (D26)
Discrimination	• I don't know; if I was applying for some job in the government, I feel like they could access [shared EHR data] somehow. I just feel like they could hurt me in terms of – like if there was something bad in them. (D26) • If it gets out, they can hit you with insurance and your insurance can go up and life insurance can be changed. There's a couple of other things in there, too, that would affect your expenses later on, insurance and whatnot. (C03) • Yeah, I also get worried that too much genetic information is gonna go out there and people could start getting blacklisted before they even are given a chance. (C28)
Irrelevance	• Sexual orientation, that's kinda too private and not relevant to anything. It's just good old nobody's business. It doesn't help anybody. I don't think that by knowing that, people can study anything that has to do with any medical, any health care – help in benefiting populations and stuff. It can't really be changed. If society doesn't accept someone's sexual orientation, by studying you're not gonna come up with some medicine to fix it. It's not something that needs to be fixed. We all are who we are. (C16)

	• Most of those diseases was going on when I was a little girl and I ain't been a little girl in 60-something years. (Q33) • Why does another healthcare organization or a commercial company need to know whether or not I had issues? (D13) • Well because that's none of their business. That's medical. That's nothing to do with government work. (M08) • I'll leave the lifestyle information at a no I don't think there’s any medicine they can come up with for ... to make us want to exercise or diet or ... (D15)
Object to abortion research	• But all the others on there, I would be okay with, but just not the abortion part because I'm totally against that. (C19) • If you're pregnant, you should stay pregnant, that's just me. I guess because of my religion. That is because of my religion. I wouldn't want nothing to do with that. (D10)

Figure 1. Willingness to share Identifiable Data, by researcher type

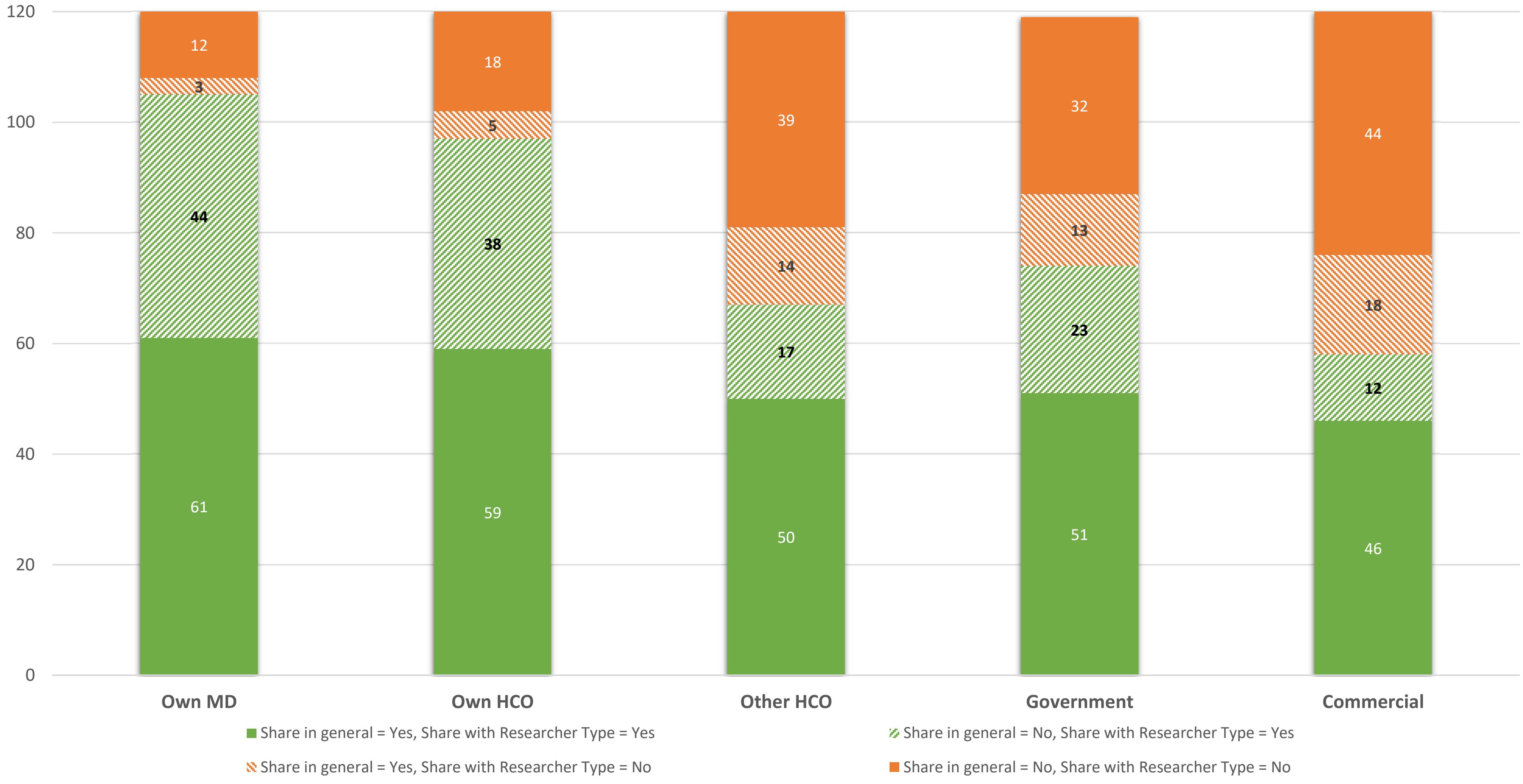

Figure 2. Willingness to share Data Type, by Researcher Type

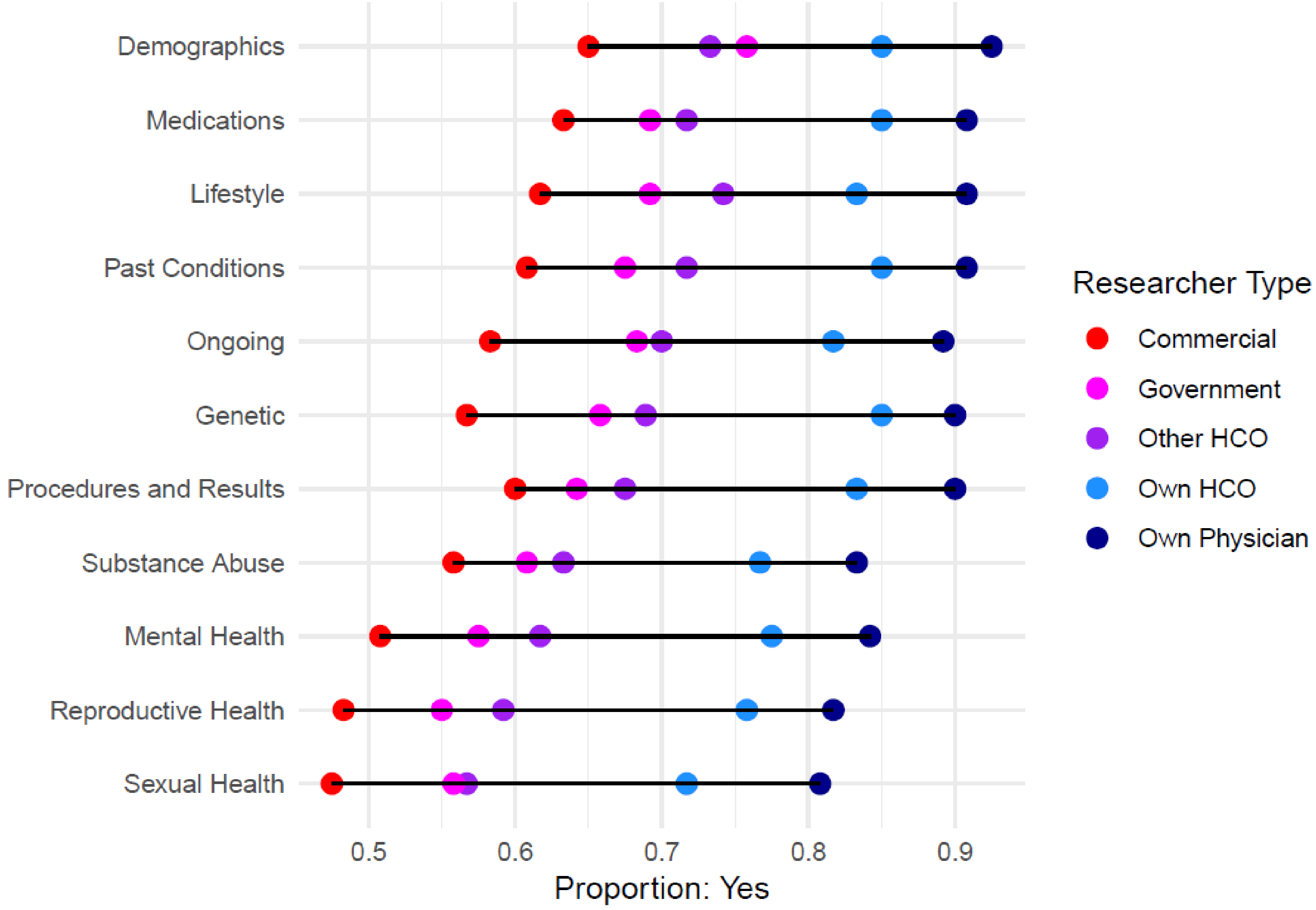

Figure 3. Willingness to share Demographic Info, by researcher type

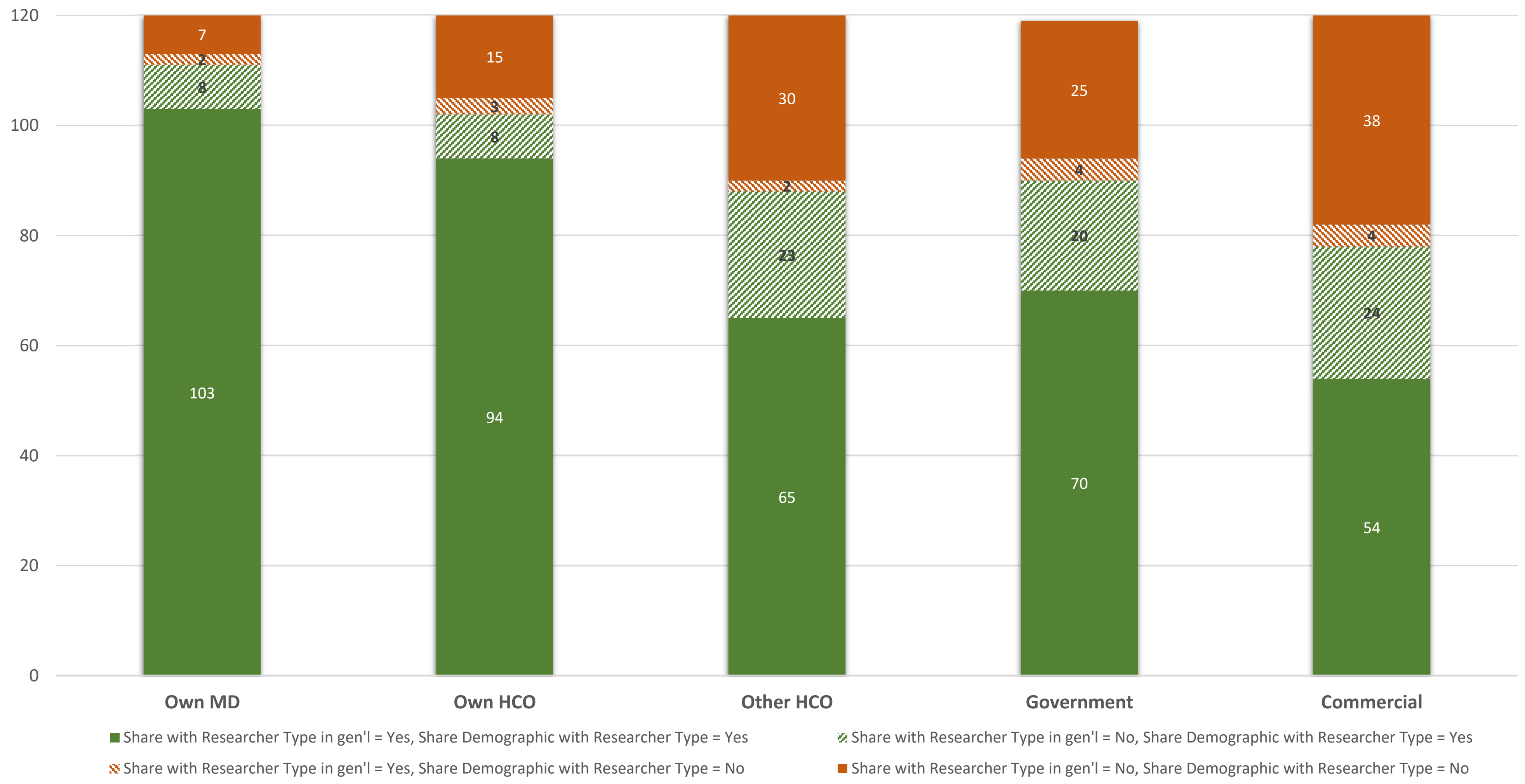

Figure 4. Willingness to share Medication Info, by researcher type

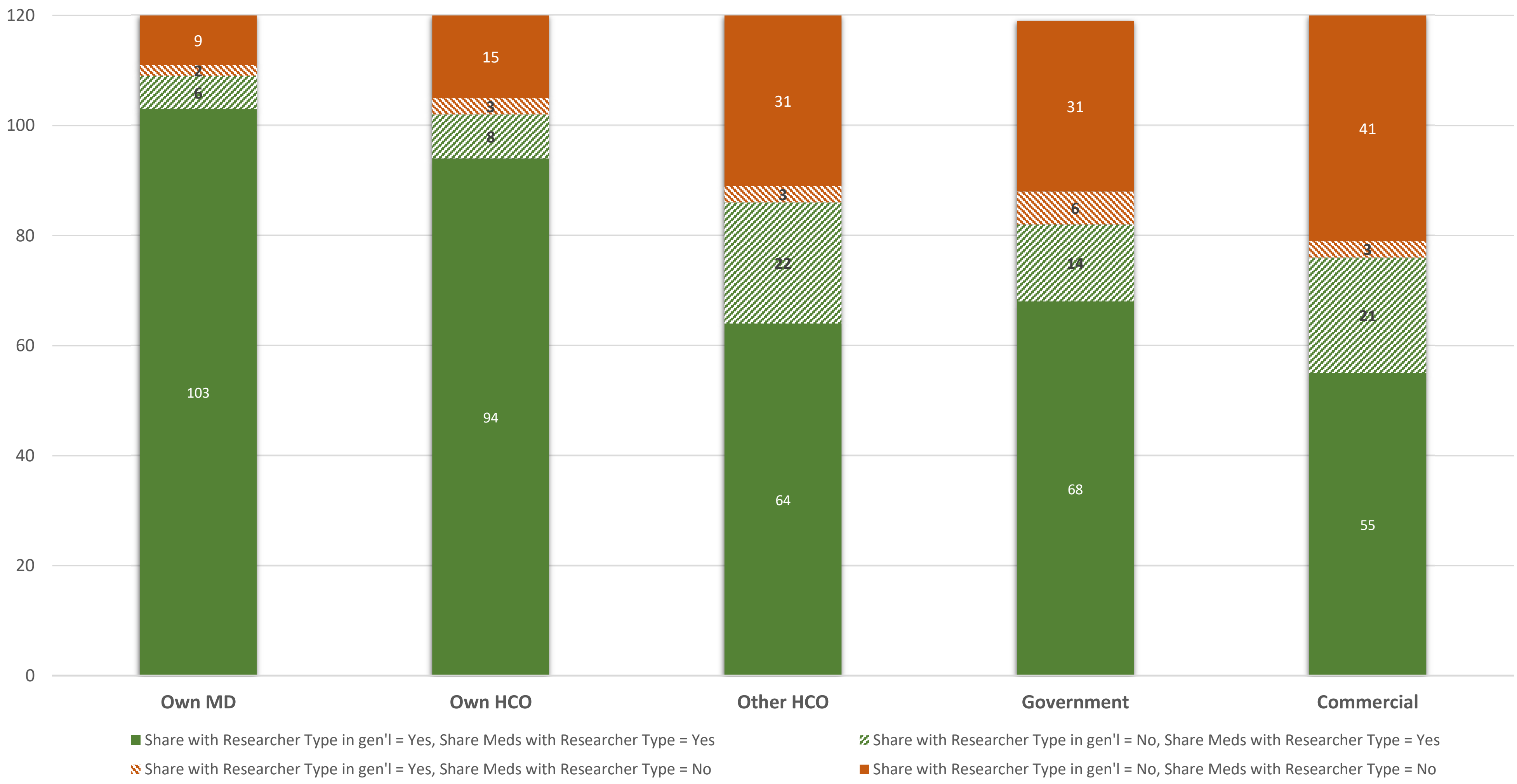

Figure 5. Willingness to share Lifestyle Info, by researcher type

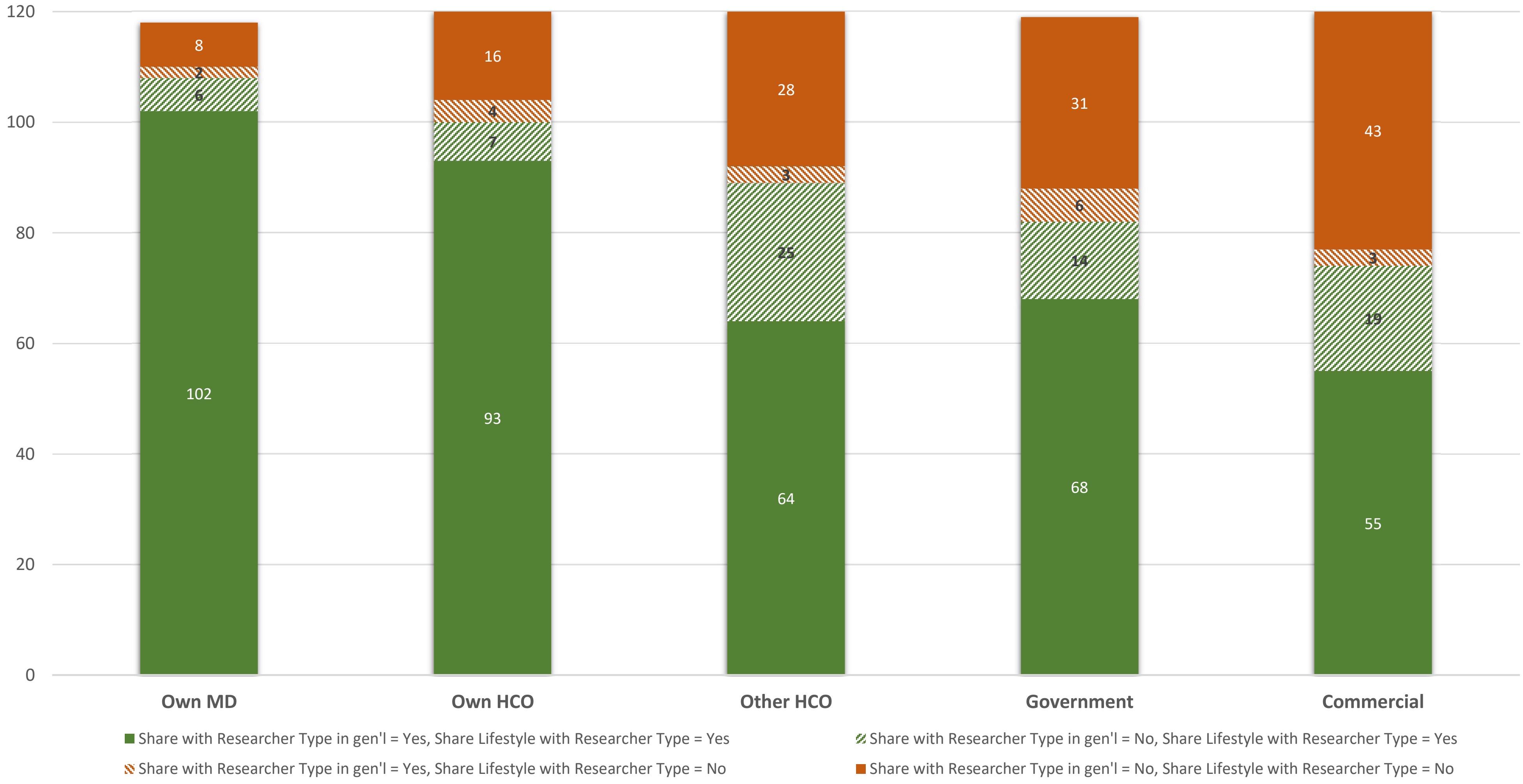

Figure 6. Willingness to share Past Conditions, by researcher type

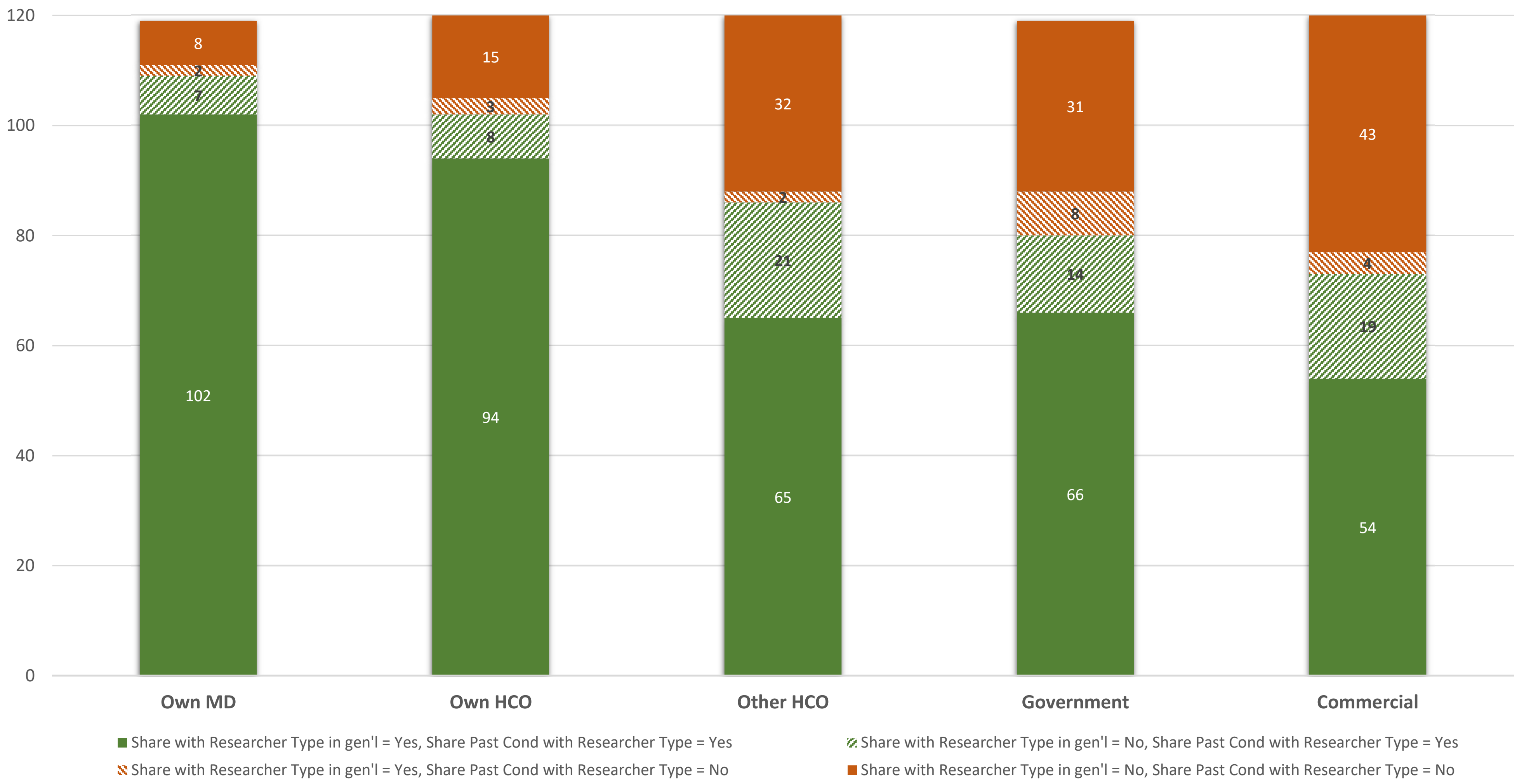

Figure 7. Willingness to share Ongoing Conditions, by researcher type

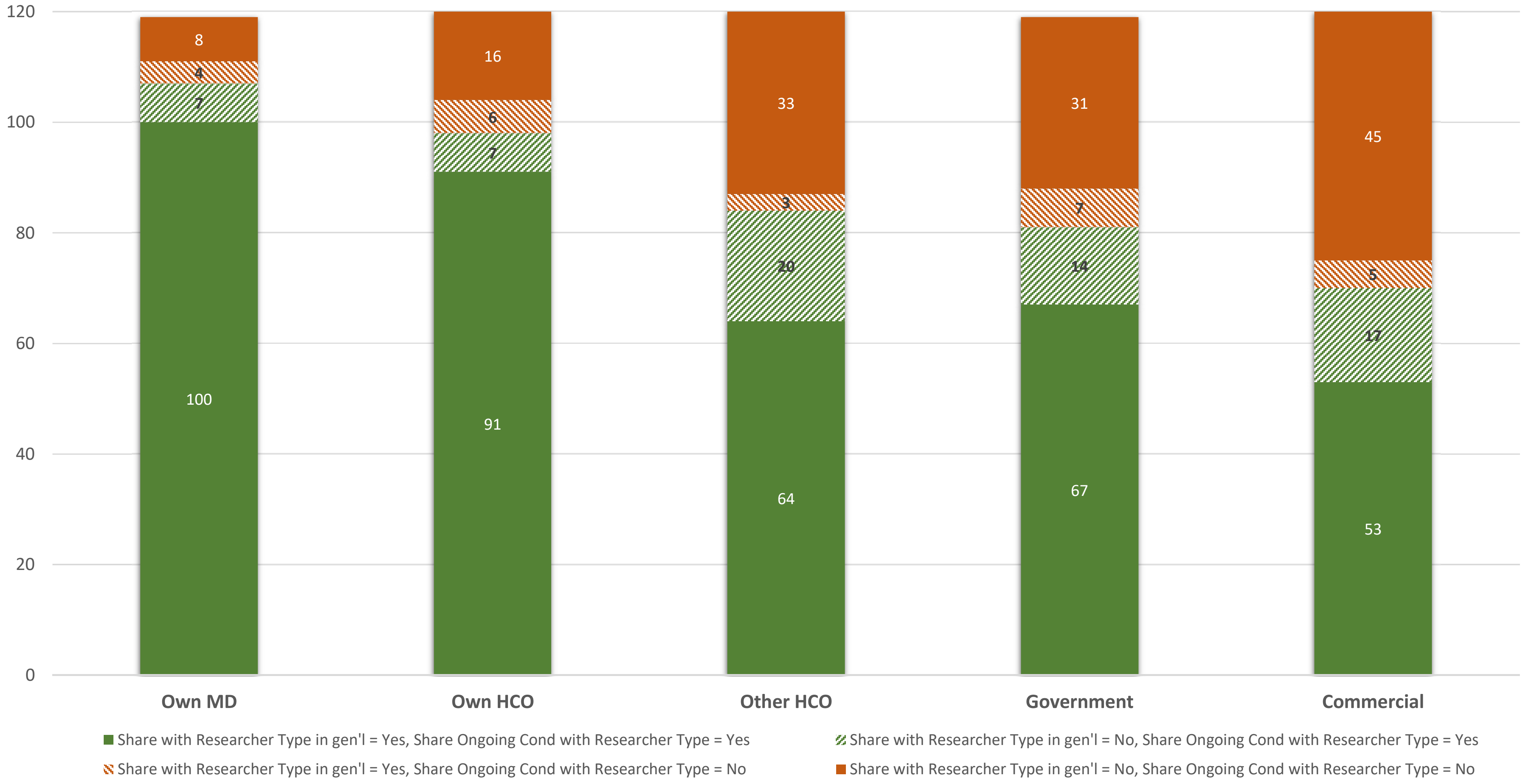

Figure 8. Willingness to share Procedures & Results, by researcher type

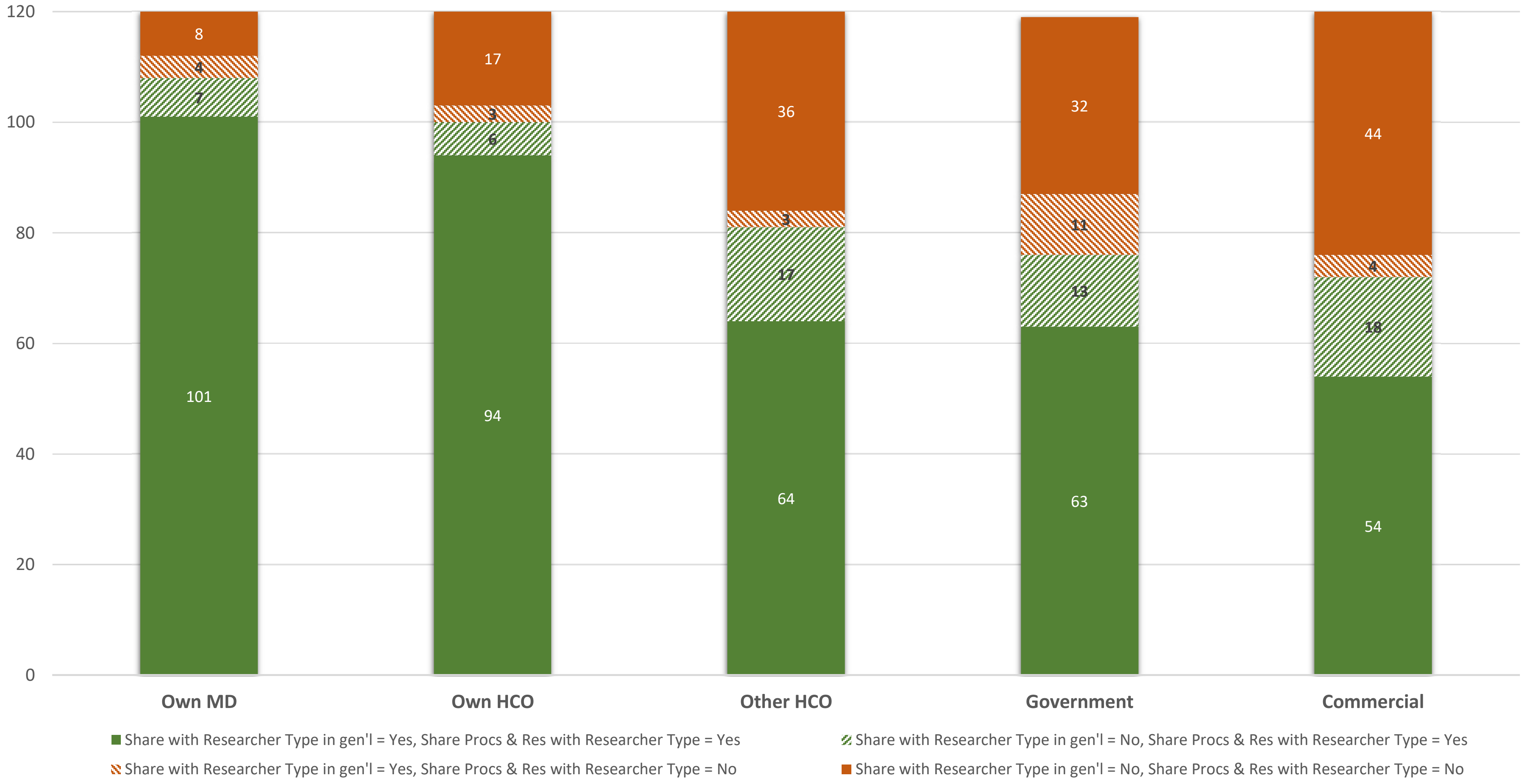

Figure 9. Willingness to share Genetic Info, by researcher type

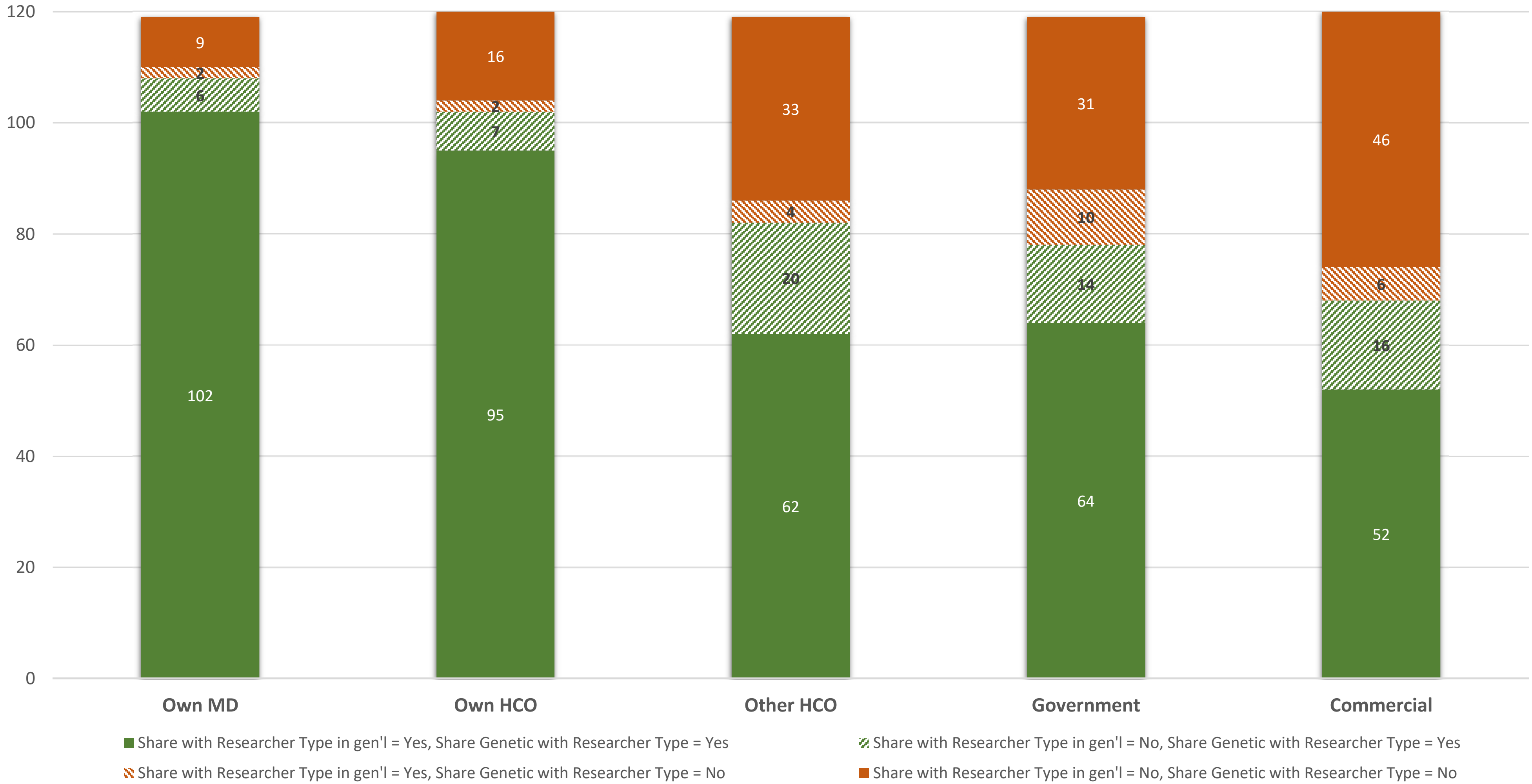

Figure 10. Willingness to share Substance Abuse, by researcher type

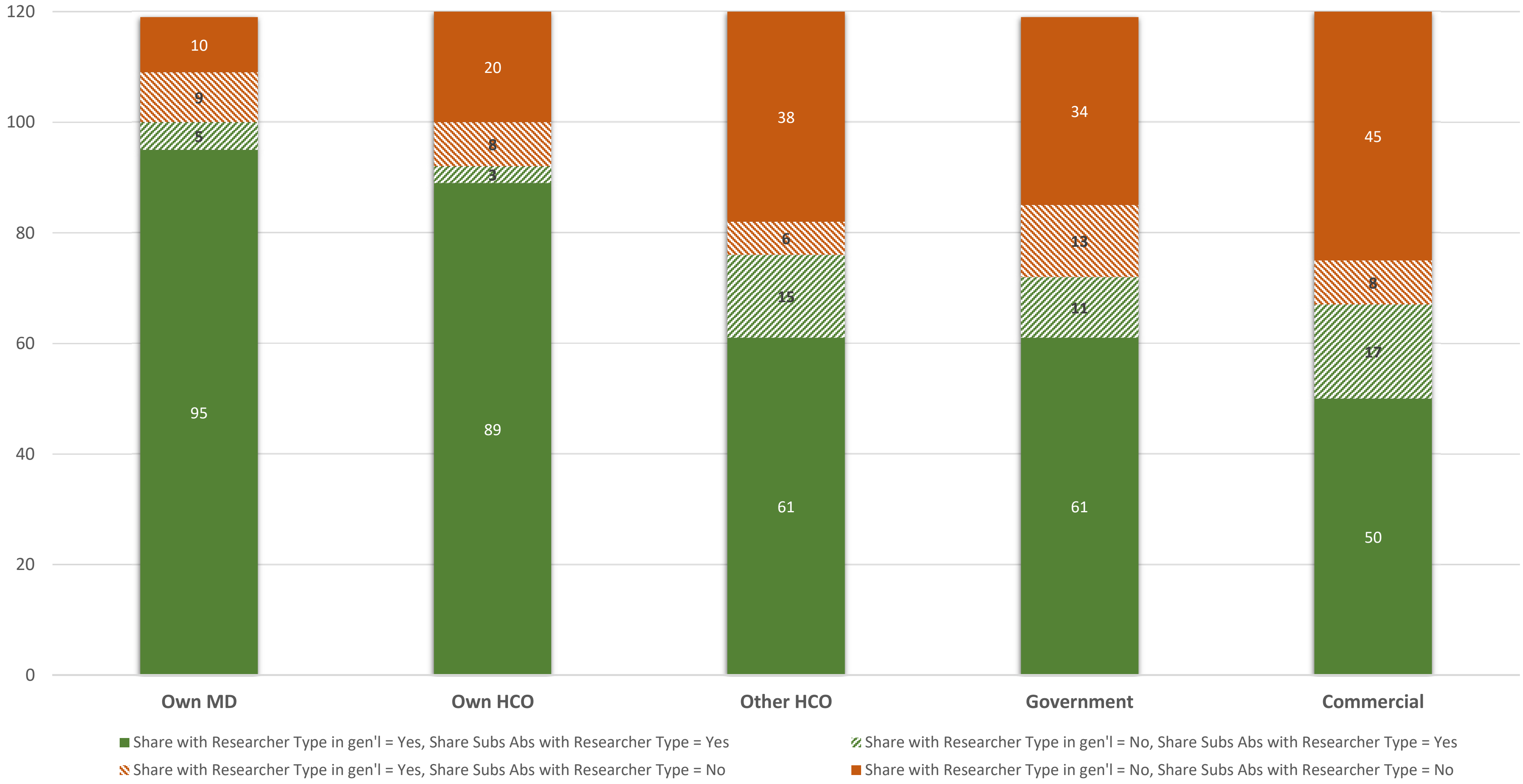

Figure 11. Willingness to share Mental Health, by researcher type

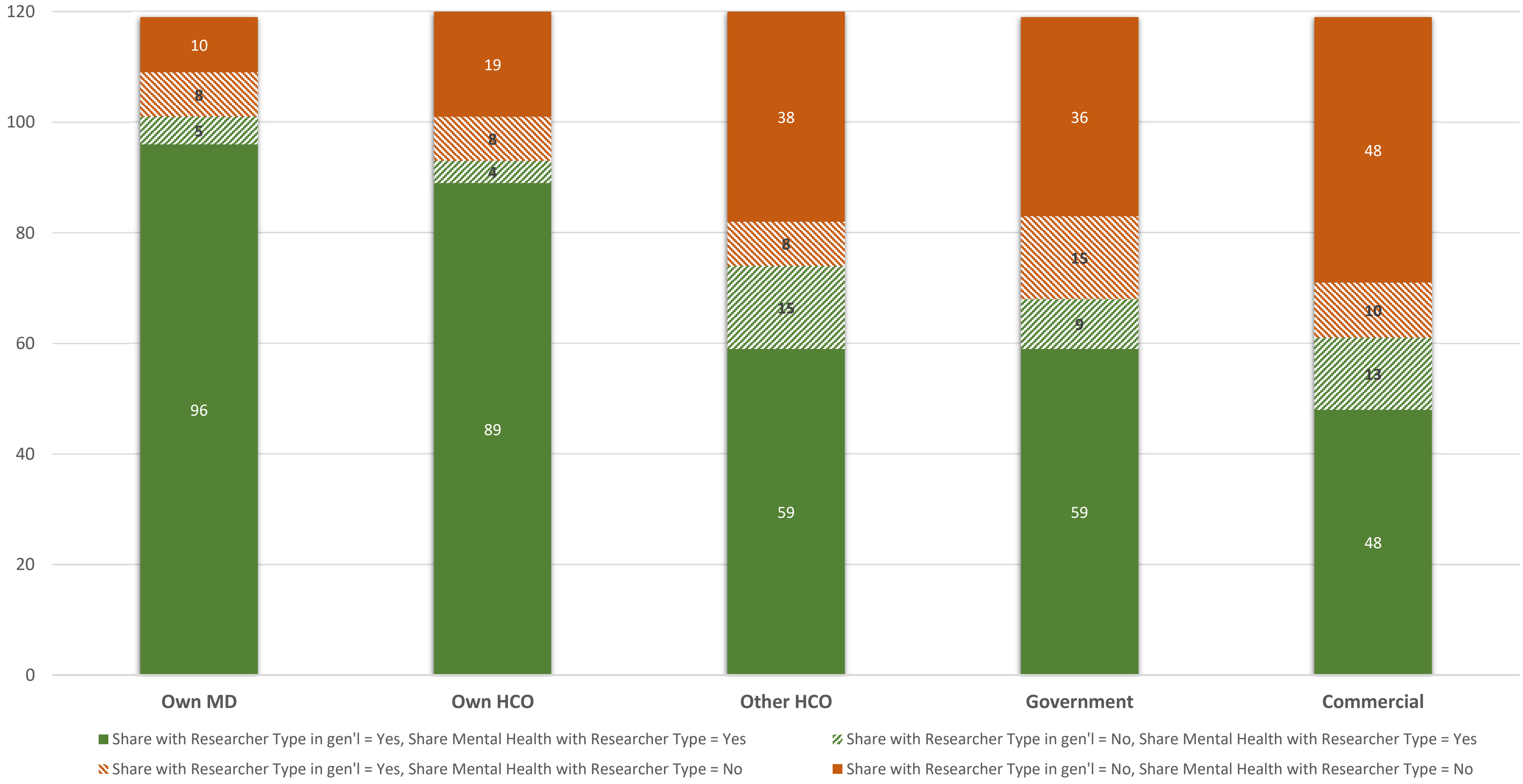

Figure 12. Willingness to share Reproductive Health, by researcher type

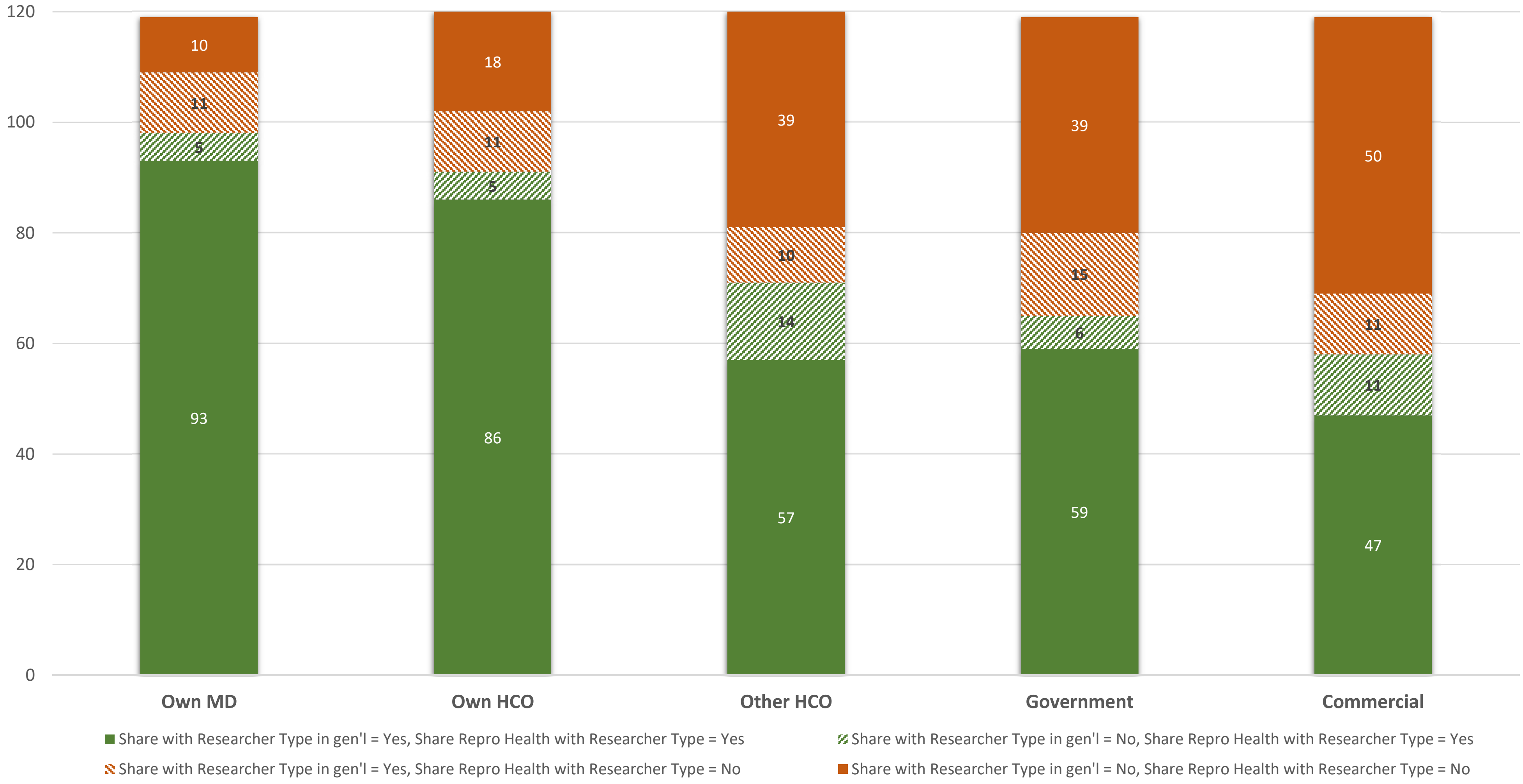

Figure 13. Willingness to share Sexual Health, by researcher type

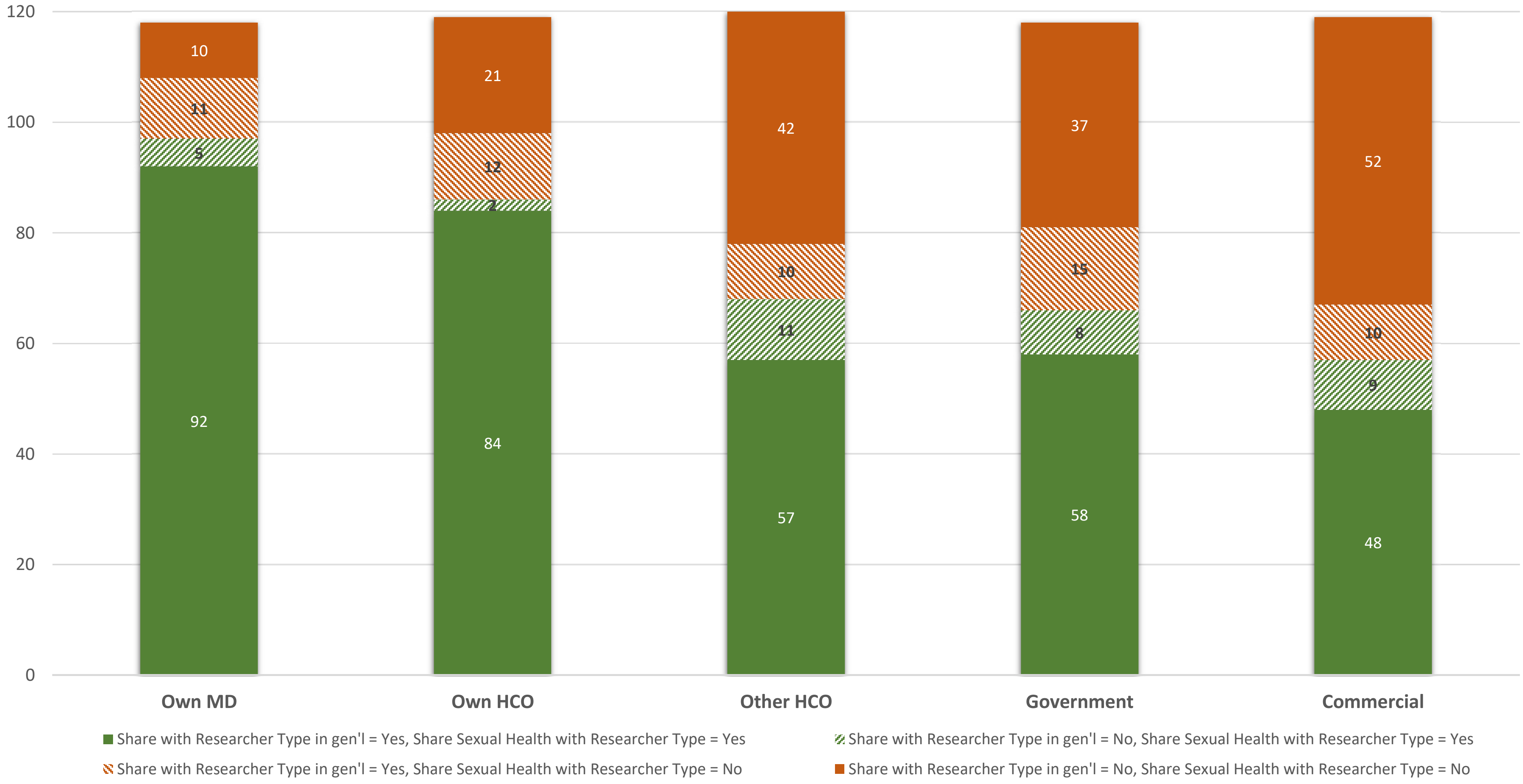

Figure 14. Willingness to share with Own MD, by data type

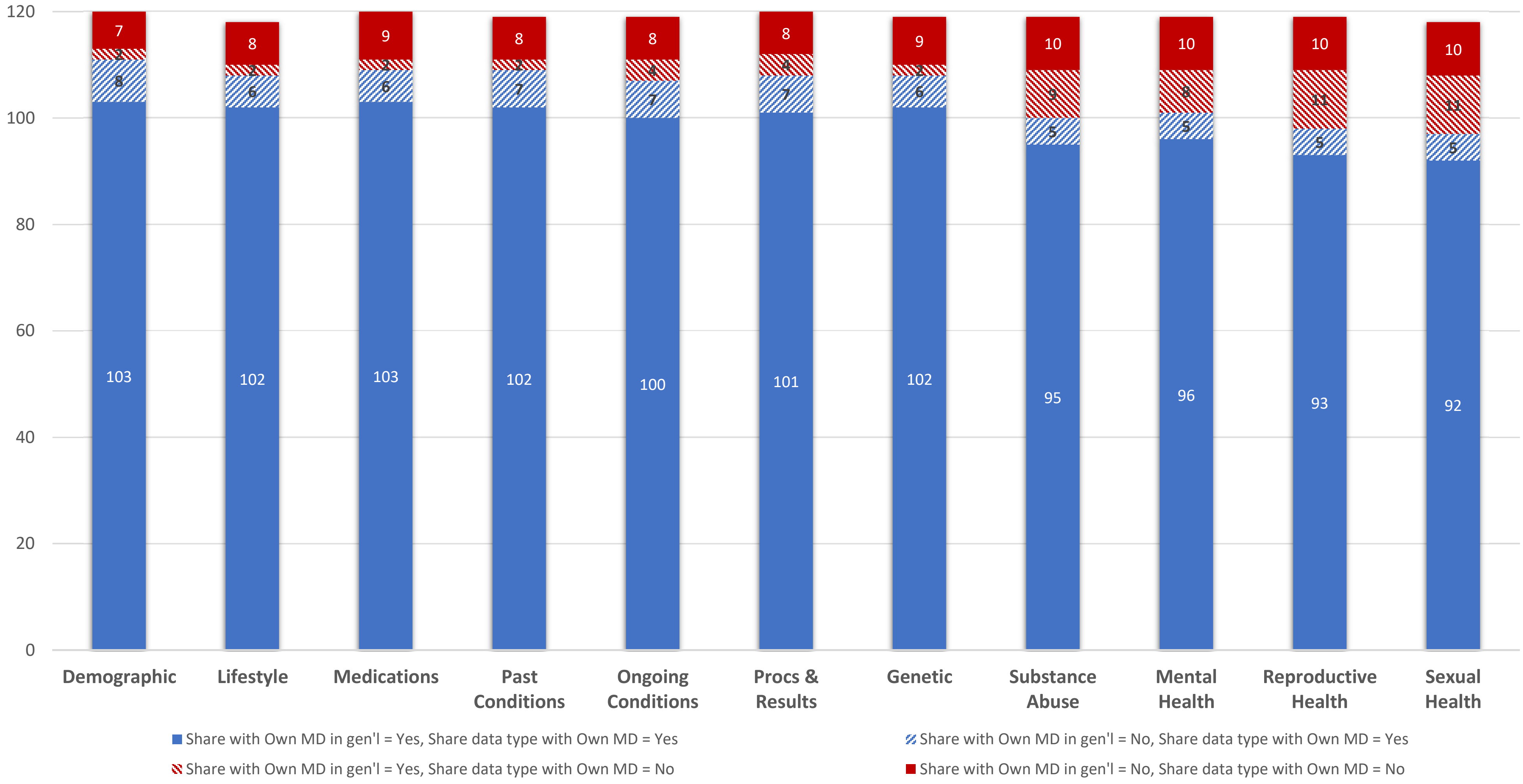

Figure 15. Willingness to share with Own HCO, by data type

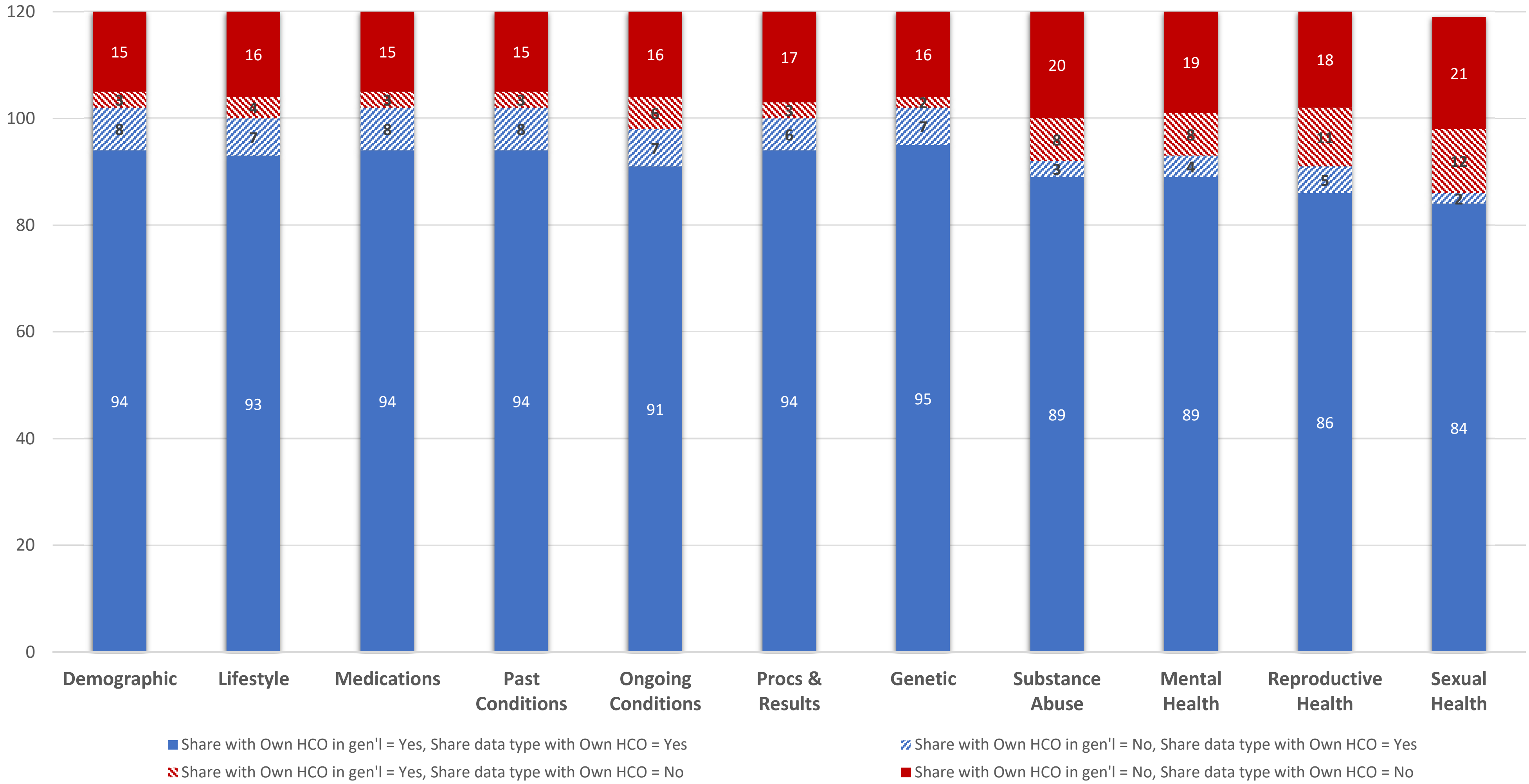

Figure 16. Willingness to share with Other HCO, by data type

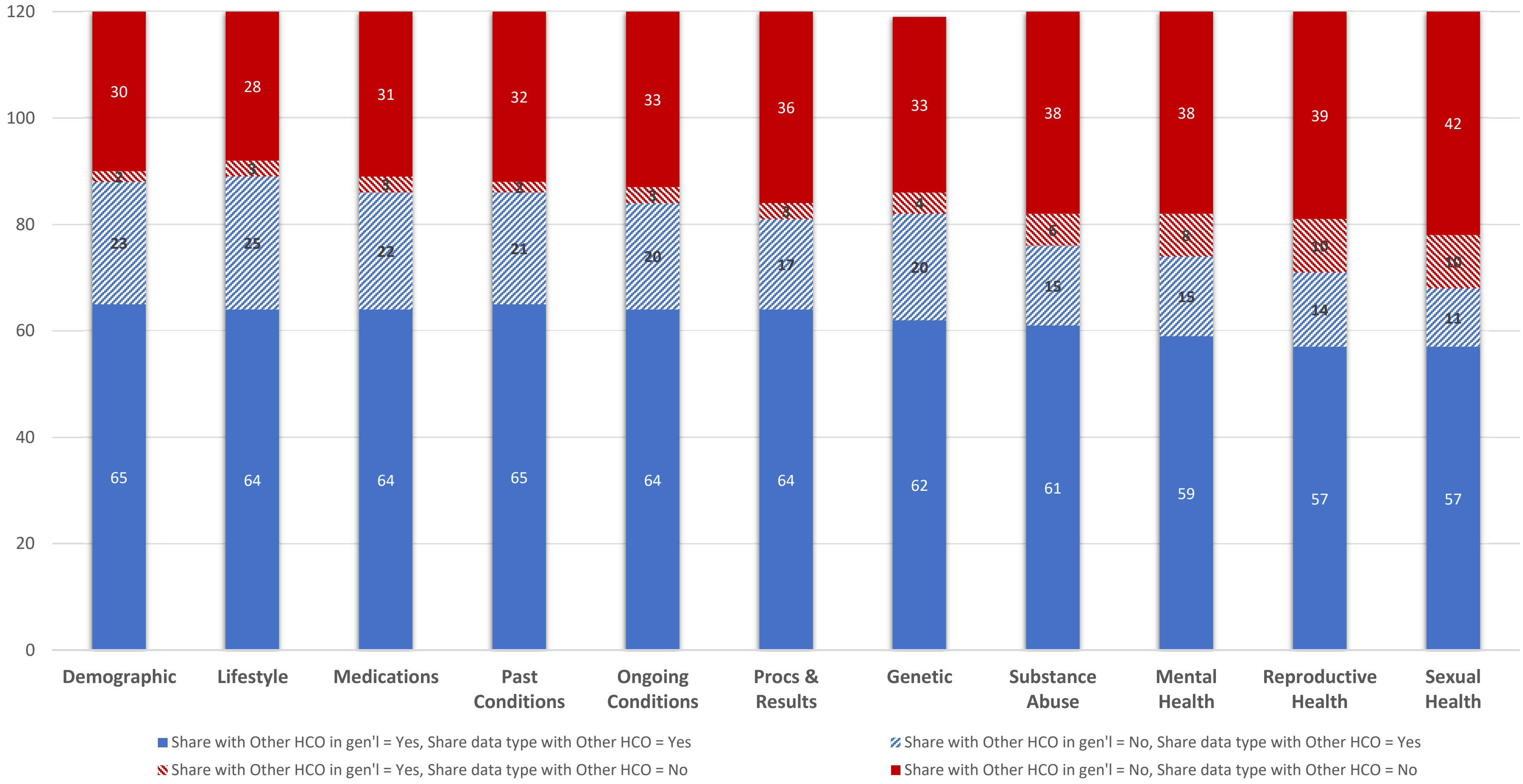

Figure 17. Willingness to share with Government, by data type

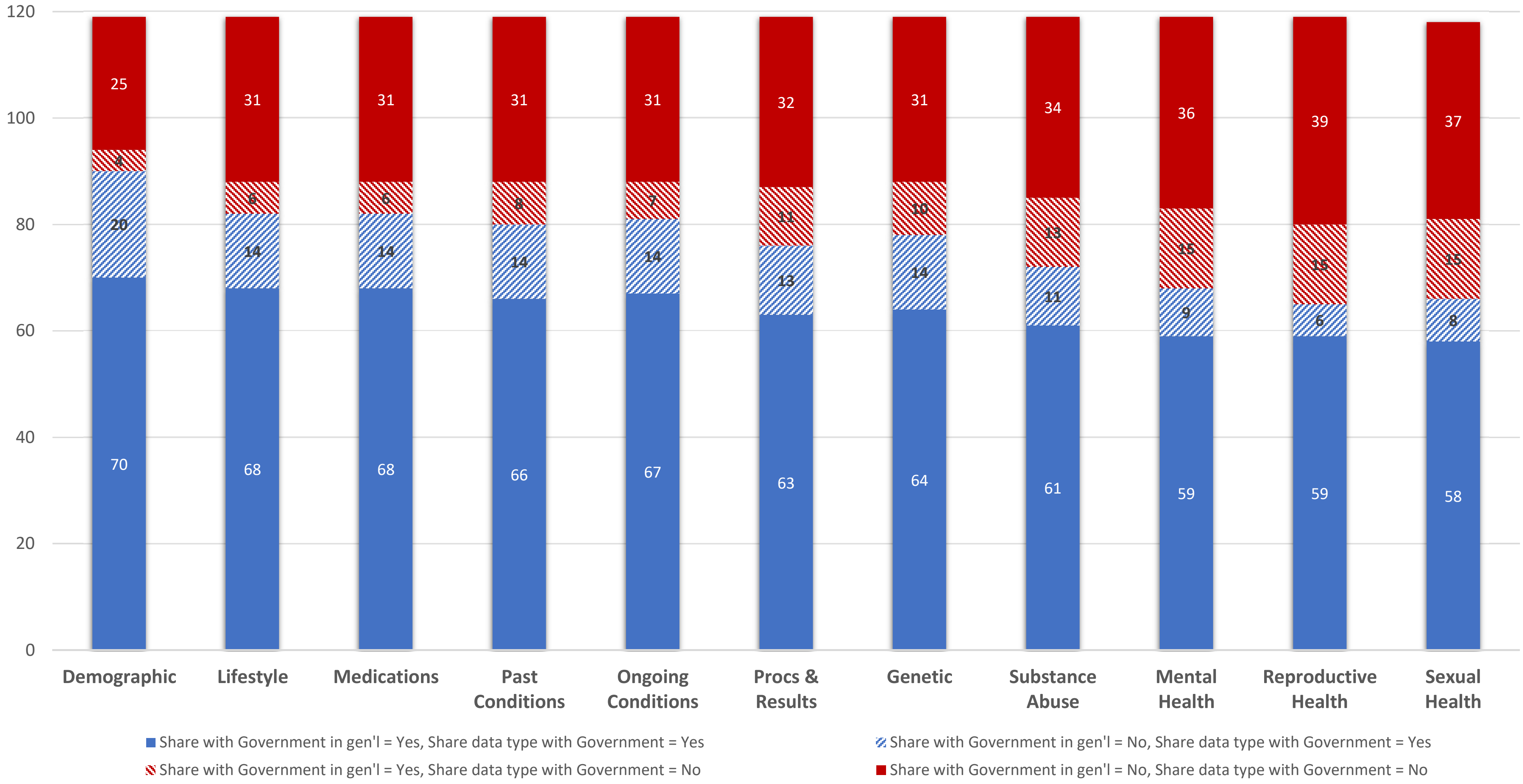

Figure 18. Willingness to share with Commercial, by data type