Attachment 3 Revisions to Data Collection

Revision or New	Change	Rationale
New	Attachment 6A - existing	The existing set of questions is not adequately capturing the
	physical activity survey	information needed to expand the knowledge of ALS risk factors.
	with a new set of physical	The new survey questions will better capture this information as
	activity questions	well as allow ALS data to be more comparable with data collected elsewhere
New	Attachment 5 - Add	For those individuals who register and are not found in
	abbreviated race question	administrative data there is no race data unless the individual
	to registration	completes survey module 1. This would give us a little
		information on race for these individuals and the categories are
		consistent with what is available in the administrative data
		because about 40% of participants do not complete Survey 1.
New	Attachment 5 – Add	We are aware that for persons with ALS (PALS) the requirement
	question about length of	to change passwords every 6 months is an additional burden that
	time until password must	may prevent them from providing valuable survey information.
	be reset	We are requesting an additional question to allow PALS to select
		a password expiration that is 6 months, 1 year or indefinite; these
		options have been approved by The Office of the Chief
		Information Security Officer at CDC.